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## **Center for Collaborative Intervention Research**

### **Abstract**

The Center for Collaborative Intervention Research (CCIR) was developed to promote and support interdisciplinary collaborations to facilitate development, testing, and evaluation of cost-effective interventions. Training, education, mentoring, and research resources have been tailored to promote collaborative opportunities for faculty at all levels. The CCIR is based on a conceptual model adapted from Pender's Model of Health Promotion and the ANA conceptualization of collaboration (interdisciplinary/interagency/community/international).

Center processes were created to promote research collaborations and included: monthly interdisciplinary seminars, intervention-focused workshops cosponsored with other disciplines, and sophisticated web-based technology which allowed Center resources to be accessed by faculty across disciplines. These efforts facilitated knowledge-sharing and close collaborations across disciplines, fostering appreciation for the unique contribution of nursing to developing intervention science. Research assistance, biostatistical and editing services were provided to developing and experienced researchers.

Outcomes included pilot funding for 15 multidisciplinary research teams. All projects included strong collaborative research partnerships. Funded studies have contributed to intervention science in the following areas: (1) interventions to improve health services for disadvantaged or marginalized populations (immigrants, victims of abuse, mentally ill); (2) to improve health outcomes (chronic illness, treatment adherence); and (3) community-based participatory research. Completed CCIR pilot grants have resulted in a range of subsequent successful submissions (RO3, R21, and RO1 level funding) in all of these areas.

Center faculty have established knowledge-sharing relationships with local, national and international research centers to further develop science surrounding the development of interventions. These relationships have provided opportunities for interdisciplinary faculty to share resources and enhance research scholarship.

**Sunny Y. Alperson, PhD, CRNP**

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## **A Grounded Theory: Natural Wholeness through Moving Meditation, the Paradigmatic Shift in Community-Dwelling Tai Chi Practitioners**

### **Abstract**

**Background:** Short term trials have claimed multidimensional benefits from Tai Chi (TC) for human health, but no theoretical framework exists to understand the mechanism of its benefits.

**Purpose:** We sought to better understand TC by giving voice to the practitioners about their experience of TC and to develop a grounded theory.

**Method:** In-depth interview data from ( $n=29$ ) self-described “committed” TC practitioners aged 49-82 years were audio-recorded, transcribed, coded and analyzed to derive a grounded theory, utilizing qualitative research methodology, Nvivo software and dimensional analysis.

**Results:** The core dimension of the practitioners experience presents TC as an agent of change. Participants experienced changing lifestyles and views of self and the world. With development of body mindfulness, TC movements and centering, TC became a meditation in motion, facilitating self exploration and new perspectives. They adopted a philosophy of “Natural Wholeness in the present moment.” Numerous symbolic meanings were linked to this new perspective, such as stillness in motion, beauty of the present moment, self acceptance, connectedness with others, universal energy and vitality and health and well-being. Based on these data, a grounded theory “Natural Wholeness through moving meditation, the paradigmatic shift in community-dwelling TC practitioners” was developed.

**Conclusion:** Participants experienced TC as a process integral to their life journey; it provided them with a vehicle for self development that benefited their health and wellbeing. Implications for future research include refinement and testing of the developed theoretical model with TC naive clinical populations of varying age groups, as well as randomized controlled clinical trials.

**Jane M Armer, RN, PhD, FAAN**

*University of Missouri Sinclair School of Nursing*

***Genetic Predisposition to Secondary Lymphedema***

**Abstract**

We know little about how genetic factors associated with other (primary) lymphatic disorders may impact the development of (secondary) lymphedema (LE) following cancer treatment. This study is a pilot for a larger-scale genetics study with primary aims to: (1) examine associations among specific candidate genes and human growth factors known to be associated with primary LE in a cohort of breast cancer patients with secondary LE, and (2) seek to identify novel genetic mutations associated with LE risk through Genome Wide Association Study (GWAS) analysis.

Institutional funding was obtained for a GWAS-design feasibility study with 96 breast cancer survivors with and without LE (48/48). Genetic material (from buccal swabs), limb volume (by perometry and circumferences), and self-reported LE-related symptoms are collected in one laboratory appointment.

Ninety-nine percent of survivors participating in an on-going longitudinal study consented to participate in the genetic pilot. Buccal swabs have provided adequate yield for DNA extraction (concentration average 174.94 ng/ul). The Illumina HumanOmni1-Quad BeadChip is the microarray used for the GWAS analysis.

These pilot findings form the basis for a larger multisite study aimed at examining genetic predisposition to secondary LE, leading to the design and timing of subsequent interventions aimed at reducing LE risk and improving overall survivorship quality of life. Additionally, findings concerning interactions among breast cancer treatments and LE genetic predisposition will have the potential to guide the selection of cancer treatment to minimize these complications when survival outcomes are equivalent across competing treatment approaches.

**Jane M Armer, RN, PhD, FAAN**

*University of Missouri Sinclair School of Nursing*

### **QUALITY OF LIFE TRENDS AMONG BREAST CANCER SURVIVORS**

#### **Abstract**

Breast cancer (BC) survivors are faced with numerous life-changing issues, including a lifetime risk for developing lymphedema (LE), a chronic condition that also negatively impacts quality of life. The goal of this research was to examine trends in scores on selected psycho-social instruments related to quality of life for a group of breast cancer survivors.

Participants enrolled following BC diagnosis and followed quarterly for 12 months, then every 6 months thereafter (N = 214). Psychosocial data were collected at baseline and annually using Problem-Solving Inventory (PSI) and Psychological Adjustment to Illness Scale Self-Report (PAIS-SR).

Preliminary analysis indicate that PSI scores remained relatively stable from post-op to 24 months (77.7 to 75.3) while scores on PAIS were lower from post-op to 24 months (28.2 to 22.6) indicating more positive adjustment. Problem-solving predicted psychological adjustment over time, with greater contribution from the Personal Control subscale ( $r = .31, p < .05$ ). Younger BC survivors had significantly higher PAIS scores reflecting poorer psychological adjustment than older survivors ( $p < .05$ ), but perceived problem-solving ability between the two groups was not statistically different.

These preliminary findings provide evidence that BC survivors continue to cope with issues related to BC diagnosis after treatment has concluded. As survivorship increases, they tend to be more positive in adjustment to dealing with disease-related issues. Younger survivors tend to report more negative adjustment than older women. Moreover, women's problem-solving is an important predictor of psychological adjustment over time, which suggests more focus on interventions containing problem-solving components is warranted.

**Suzanne Bakken, RN, DNSc, FAAN**  
*Columbia University*

## **Center for Evidence-based Practice in the Underserved**

### **Abstract**

The aims of the Center for Evidence-based Practice in the Underserved (CEBP) are to: 1) Facilitate the development of biobehavioral research capacity in self-management for underserved populations through the funding of research studies and the implementation of four interdisciplinary cores (Administrative; Design, Methods, Biostatistics, and Economic Analysis; Self-Management, Biobehavioral, and Informatics; Dissemination and Translation); 2) Implement and maintain a social software-based approach, building upon the infrastructure of the CTSA "WorkWeb" Portal to enable interdisciplinary researchers in self-management to communicate and collaborate through a variety of information and communication technologies and services; 3) Enhance the expertise of CEBP investigators in informatics-based approaches that enable self-management interventions for underserved populations in a manner appropriate to culture and level of health literacy; 4) Develop the expertise of CEBP investigators in application of appropriate economic methods and analyses for self-management studies in underserved populations; 5) Facilitate dissemination of research findings into the interdisciplinary scientific literature and translation into practice and policy; and 6) Implement a formative and summative evaluation plan. Our approaches capitalize on outstanding interdisciplinary collaborations and resources and the use of innovative information technologies including social/collaborative and knowledge management software to facilitate the development of biobehavioral research capacity for scientists conducting self-management research in underserved populations. CEBP feasibility study investigators apply CEBP core resources to identify and test strategies to enhance self-management in four vulnerable populations (adolescents with diabetes, persons living with HIV, diabetics with hypertension, and community-dwelling elders at risk for injury by falls).

**Taura L. Barr, PhD, RN**

*West Virginia University School of Nursing and Department of Neuroscience and the National Institute of Nursing Research*

## **Inflammatory Regulation as a Biomarker of Ischemic Stroke Diagnosis: Evidence from Gene Expression Profiling**

### **Abstract**

**Aim:** The objective of this study was to identify peripheral blood biomarkers for differential diagnosis of acute ischemic stroke and novel targets for stroke therapeutics through gene expression profiling.

**Methods:** Peripheral blood was collected from n=39 MRI diagnosed ischemic stroke patients  $\geq 18$  years of age and n=25 Non-stroke control subjects. RNA was extracted from whole blood stabilized in Paxgene RNA tubes, amplified, and hybridized to Illumina humanRef-8v2 bead chips. Gene expression was compared in a univariate manner between stroke patients and control subjects using *t*-test. Inflation of type one error was corrected by Bonferroni family wise error rate of  $p < 0.05$ . Validation was performed by QRT-PCR Taqman gene expression assays. Expression data was further interpreted through Ingenuity Systems Pathway analysis.

**Results:** Mean time from symptom onset to blood draw was 10:06hrs  $\pm 6:31$ . Stroke patients were significantly older than control subjects ( $t = -4.03$ ;  $p = 0.000$ ). A nine gene profile was identified in the whole blood of stroke patients. Five of these nine genes were identified in a previously published expression profiling study of stroke and are therefore likely candidates for stroke: (*ARG1*; *CA4*; *LY96*; *MMP9*; *S100A12*). Pathway analysis revealed toll like receptor (TLR) signaling as a highly significant pathway present in the whole blood of stroke patients.

**Conclusion:** This study supports gene expression profiling of peripheral whole blood for the identification of biomarkers of stroke. These results also suggest activation of the innate immune system through TLR signaling as a mediator of response to ischemic stroke.

**Mandy J. Bell, BSN, RN (Predoctoral Fellow, Ruth F. Kirschstein National Research Service Award)**

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## **Genomics of Endoglin Pathway in Preeclampsia**

### **Abstract**

Preeclampsia (PE) represents a hypertensive pregnancy disorder that is associated with significant maternal and fetal/neonatal morbidity and mortality. Gene expression studies identified endoglin (ENG), a co-receptor of the TGF- $\beta$  family involved in regulation of trophoblast invasion and vascular endothelial function, as a factor potentially involved in PE development. Because investigation of the ENG pathway at the molecular level is needed, this pathway specific, candidate gene, case-control research study seeks to: 1.) investigate variation in maternal genes involved in the ENG pathway for impact on development of PE; 2.) explore variation in maternal/fetal dyad genes involved in the ENG pathway for impact on development of PE. Maternal/fetal dyad DNA samples (N=1,478 maternal and N=1,478 fetal/neonatal samples) and phenotype data have been obtained from the Prenatal Exposures and Preeclampsia Prevention study. Cases= women diagnosed with PE (N=225 maternal and N=225 fetal subjects) based on criteria for blood pressure, proteinuria, and hyperuricemia. Controls= women who remained normotensive during pregnancy and did not develop proteinuria or hyperuricemia (N= 1253 maternal and N= 1253 fetal subjects). Cases will be matched to controls for ancestry, parity, and maternal age. i-PLEX will be utilized for genotype collection and HAPLO.STATS package will be utilized for haplotyping. Statistical analysis will include chi square tests, univariate and multivariate, heirarchical logistic regression, and transmission disequilibrium testing. Findings from this study may explain variability in susceptibility to PE, increase knowledge of pathophysiologic mechanisms involved in PE development, and assist in the design/implementation of interventions aimed at prevention, detection, and treatment of PE.

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## **Diet & Gene Expression in Obese Renal Transplant Recipients**

### **Abstract**

**Aims:** Compare differences in diet and gene expression between weight gainers and non-weight gainers at 6 months following kidney transplantation (txp).

**Methods:** A prospective design obtained diet and clinical data at txp and 6 months post txp from 37 kidney recipients (51% M, 38% C, mean age 51.5) enrolled in a 5-yr NINR funded study. RNA was isolated from subcutaneous adipose tissue obtained during surgery and examined by Affymetrix Human Gene 1.0ST Array. Analysis was performed using GeneSpring GX and Gene Indexer software programs. 24-hour dietary recalls were analyzed with Nutritional Data System for Research. Analysis compared weight gainers ( $\geq 5\%$  weight gain from baseline to 6 mo) and non-weight gainers.

**Results:** Approximately 58% of patients gained  $\geq 5\%$  and 33% gained  $\geq 10\%$  by 6 mo., with some gaining up to 40lbs. There was no significant change in intake over this period, possibly explained by the large variation in intake. Notably, at all time points fat and carbohydrate intake were higher and fiber intake was 50% less than daily recommended intake. Microarray analysis identified 613 genes with differential expression between groups. Interestingly, several of the genes have already been associated with obesity previously.

**Conclusions:** Weight gain was significant, yet did not correlate with intake indicating that other factors (i.e., genetics) play roles in the susceptibility to become obese. This is the first longitudinal data documenting dietary intake and gene expression in renal transplant recipients and is a primary step in identifying at risk groups and designing an obesity prevention intervention.



**Constance E. Cephus**

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**Impact of GRK5-Leu41 on Clinical Outcomes of Children with Heart Failure Receiving Standard Therapy: Research Proposal**

**Abstract**

The basis for drug therapy in the treatment of symptomatic heart failure in children is primarily the result of anecdotal, pediatric clinical experience, case series and extrapolated data from adult clinical trials. The addition of  $\beta$ -adrenergic receptor ( $\beta$ -AR) antagonists to routine management of children with ventricular dysfunction was prompted by reports of improved survival and decreased hospitalization in adult patients.  $\beta$ -blocker therapy appears intuitive, since chronic stimulation of  $\beta$ -AR leads to ventricular chamber dilation, ventricular dysfunction and death. However, retrospective studies and small case series conducted in the pediatric population have not demonstrated overwhelming evidence that  $\beta$ -blocker therapy is appropriate for children with heart failure. Recent adult literature has indicated that a G protein kinase 5 (GRK-5) allele may play a significant role in desensitizing  $\beta$ -ARs, thus, acting as a protective mechanism and modifying outcomes of adults with heart failure. The primary aim of this study is to prospectively evaluate the impact of GRK5-Leu on the outcomes of children with symptomatic heart failure that is not amenable to surgical/catheter intervention. The specific aims: 1) to correlate phenotypic response to  $\beta$ -blocker therapy with the presence of GRK5 alleles 2) to correlate qualitative and quantitative echocardiographic indices with the presence of GRK5 alleles 3) to correlate length of stay, episodes of exacerbation, BNP levels and all cause mortality.

**Garrett K. Chan, PhD, APRN, FPCN, FAEN**  
*Stanford Hospital & UCSF School of Nursing*

## **Genetic Variation and Dyspnea after Morphine Administration in Acute Exacerbations of COPD**

### **Abstract**

#### **Background and Significance**

Respiratory distress and dyspnea can be anxiety provoking and give the patient a feeling of suffocation. Therapies for dyspnea in acute exacerbations of COPD (AECOPD) in emergency care include disease-modifying therapies without palliative interventions.<sup>1, 2</sup> In contrast, palliative care has a long tradition of using opioids to control dyspnea. The exact mechanisms of opioids to control dyspnea are unknown. Small studies demonstrated variable effects of opioids on dyspnea.<sup>3-5</sup> One possibility for the variability may be due, in part, to genetic variation.

#### **Purpose**

The purpose of this pilot study is to understand the biobehavioral presentation of patients with dyspnea with AECOPD and to describe the metabolic pathways that mediate the effects of morphine on dyspnea using a genome wide expression approach.

The specific aims are:

- 1. Conduct a genome wide expression study to identify the novel (not-yet-known) genomic and transcriptome expression profile of dyspnea.**
- 2. Compare the genomic and transcriptome expression profiles of those patients who responded, who did not respond, and who experienced side effects to morphine for dyspnea.**

#### **Methods**

This prospective quasi-experimental study will recruit patients who present to the ED with severe dyspnea with a presumed diagnosis of AECOPD.

#### **Implications**

Approaching this phenomenon using a genome-wide methodology that does not require *a priori* propositions nor rely on our limited knowledge will describe the interconnections of these metabolic pathways and will help advance our understanding of this distressing symptom and create possibilities for effective interventions.

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## **Symptoms and quality of life in diverse patients undergoing hematopoietic stem cell transplantation**

### **Abstract**

**PURPOSE:** To Identify and compare quality of life (QOL) and symptom severity and prevalence of African American, Latino, and non-minority persons having hematopoietic stem cell transplantation (HSCT) at multiple time points.

**PATIENTS AND METHODS:** Data were collected from 164 patients at 8 points from pre-transplant to 100 days post-transplant. The M. D. Anderson Symptom Inventory- BMT (MDASI - BMT) measured symptom severity and its impact. The Functional Assessment of Cancer Therapy for BMT (FACT-BMT) measured QOL.

**RESULTS:** Over time, symptom severity was significantly correlated with quality of life and patients who had allogeneic transplants with myeloablative regimen showed more severe symptoms and poorer quality of life. The five worst symptoms were pain, sleep, distress, fatigue, and drowsiness. Male patients reported fewer of these five worst symptoms than female patients. African American males reported more pain than African American females. Hispanic patients reported fewer problems with sleep, fatigue, and drowsiness than white non-Hispanic patients. No significant differences were found in symptom severity, symptom interference, quality of life and ECOG performance status between Hispanics and African-Americans over time. Patients whose functional status was good had fewer of the five worst symptoms and higher quality of life.

**CONCLUSION:** Type of transplant and preparatory regimen are the most important aspects to consider when managing symptoms and quality of life. This information is important for providing anticipatory guidance and support needed during the transplantation experience, and to explore in future research to understand mechanisms involved in symptoms after HSCT and to develop additional effective interventions.

**Arseima Y. Del Valle-Pinero, PhD; Angela C. Martino, BSN; Dan Wang, PhD; and Wendy A. Henderson, PhD.**

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## **Overexpression of Chemokine C-C Motif Ligand 16 (CCL16) in Irritable Bowel Syndrome (IBS) Patients**

### **Abstract**

**AIM:** Irritable bowel syndrome (IBS) is a considerable health problem with limited clinical treatment options. The economic consequences of IBS in the United States are estimated to be over \$30 billion per year. IBS is defined by Rome III criteria as chronic abdominal pain and changes in stool frequency or form for at least three months. There is evidence that molecular mechanisms behind IBS may include an underlying subclinical inflammatory mechanism. In this study the genetic expression of inflammatory biomarkers in IBS patients was evaluated.

**METHODS:** Patients (n=8) that met criteria for IBS for longer than six months and age-matched healthy controls (n=8) were recruited to a natural history protocol. The expression of 96 genes of interest in inflammatory response was then analyzed using a custom quantitative real-time PCR array.

**RESULTS:** Chemokine C-C motif ligand 16 (CCL16) was upregulated by more than 8-fold in IBS when compared to healthy controls. For patients with constipation predominant IBS this difference was very significant ( $p < 0.0001$ ).

**CONCLUSIONS:** To better understand the molecular mechanisms behind IBS is critical that we analyze the gene expression of these and other biomarkers. This may aid in the discovery of novel targets for the treatment and symptom management of IBS patients.

**Joan E. Dodgson, PhD, MPH, RN & Mary F. Oneha, PhD, APRN**

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## **PRENATAL PTSD IN A MULTI-ETHNIC COMMUNITY**

### **Abstract**

The aims of this study were to compare socio-demographic and health-related variables and to explore the relationships among these variables in prenatal women grouped by positive and negative PTSD screens. A case-controlled design was used to gather retrospective medical record data from pregnant women over the age of 20, who received prenatal care from Waianae Coast Comprehensive Health Center, Oahu (Hawaii). The power analysis was met. Women who screened positive for PTSD ( $n = 68$ ) were matched on marital status and ethnicity with the control group ( $n = 108$ ). Grouped data were summarized using descriptive statistics. Physical violence had been experienced by 68% of study participants. The predictors of PTSD (physical trauma, lack of family support, family stress, depression, CPS involvement, perinatal loss, parity greater than 2, and substance abuse) were first examined separately (one model for each) via chi-square tests, and then simultaneously (all in the same model) via logistic regression. Physical trauma, lack of family support, family stress and depression were statistically significant ( $p < .05$ ) in both models. The incidence of PTSD in prenatal women is unknown and has not previously been explored in Asian American and Pacific Islander women. Although a distinct constellation of social variables identified the women with a positive screen, high levels of violence was the norm in this sample. Initiating PTSD screening in the prenatal period may identify women with higher risk for multiple social and health issues and provide a window of opportunity to provide behavioral health services.

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**Dr. Susan G. Dorsey**

*University of Maryland School of Nursing and Program in Oncology*

**UMB Center for Pain Studies**

**Abstract**

This year more than 1.5 million new cancer cases will be diagnosed and nearly 11 million Americans currently have a history of cancer. The annual costs for medical care for patients with cancer was an estimated \$219 billion in 2007, with \$132 billion more spent for indirect costs including lost work productivity. Mortality rates are declining, in large part due to earlier diagnosis and improving treatment strategies. Unfortunately, improved survival rates are accompanied by both disease and treatment complications that can severely decrease quality of life and significantly reduce functional status. One of the most significant and debilitating complications associated with cancer treatment is pain. An estimated 33-50% of all cancer patients experience pain caused by tumor invasion, diagnostic/therapeutic procedures, and/or side effects of cancer treatment modalities (chemotherapy or radiation) at some point in the cancer trajectory. A group of interdisciplinary pain researchers at the University of Maryland recently formed a Center for Pain Studies and obtained P30 funding from NINR P30 NR011396). The aims of the Center are to support funded pilot studies by new investigators and to increase the quantity and quality of cancer pain research project on the campus and beyond. Four Core Facilities, including Administrative, Biobehavioral, Genetics and Biostatistics, provide the infrastructure and substantive support to assist both new and established investigators with their cancer pain research programs. This Center will enable us to formalize, enhance, and sustain our interdisciplinary research efforts with the hope that we will contribute significantly to the World-wide effort to eradicate cancer pain.

**Jennifer R. Dungan, PhD, RN**  
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## **Survival- and Age-Variant Genes for CAD: Candidate Genes or Evidence of Bias?**

### **Abstract**

Sudden death is the *initial presentation* of coronary artery disease (CAD) in 50-60% of people. CAD prevalence and mortality increase with age. We hypothesize that CAD candidate genes vary by survival and age, potentially biasing gene associations with CAD.

We aimed to: 1) To characterize survival and age biases for selected CAD candidate genes in the Duke CATHeterization GENetics Study; 2) To determine the effect of survival and age biases on associations with genes and CAD.

We performed a secondary analysis of 1,885 subjects in the Duke CATHGEN dataset was performed; 36 single nucleotide polymorphisms (SNPs) from 6 CAD candidate genes were selected to explore survival and age biases. Traditional survival analyses were performed. Logistic regression models were fit for CAD diagnosis and each gene (independent variables), controlling for age, sex, race, and death (survival). Interaction terms for age\*survival were evaluated for 370 SNPs in a model for CAD index.

Preliminary data implicate five SNPs corresponding to the limbic system associated membrane protein (*LSAMP*) and kalirin (*KALRN*) genes that significantly varied by or had interactions with survival. A validation set of ~5,000 CATHGEN subjects is being genotyped. Age interaction evaluation is underway.

Various CAD candidate genes vary significantly by survival and age, providing evidence of survival and age effects in gene associations with CAD. Controlling for survival and age in gene associations may be important to refining the genetic contribution to CAD. These SNPs may also represent candidate genes for cardiovascular survival and/or aging phenotypes.



**Jennifer Harrison Elder, PhD, RN, FAAN**

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*Professor and Associate Dean for Research, University of Florida's College of Nursing*

## **PERCEIVED STRESS AND FAMILY DYNAMICS IN FATHERS AND MOTHERS OF CHILDREN WITH AUTISM**

### **Abstract**

**Background:** Literature regarding fathers of children with autism remains sparse, and because mothers are the more common intervening parent, few training methods have focused on fathers. Presented are findings from a study evaluating novel father-directed training methods for children with autism.

**Methods:** As part of our 5-year NINR-funded study, we analyzed baseline data from 19 families and compared mother and father scores from the Parental Stress Inventory (PSI) and the Family Adaptability and Cohesion Scale II (FACES II) before and after a 12-week in-home training protocol. Descriptive statistics and paired t-tests were used to describe and statistically test whether pre-intervention differences existed between mothers and fathers in families having a child with autism.

**Results:** No statistically significant differences were found between mothers and fathers who scored at or above the 90<sup>th</sup> percentile on the PSI at baseline indicating clinically significant stress levels. On average, fathers total PSI decreased 7.3 (sd=16.6, p=0.07) points and mothers total PSI decreased 6.5 (sd=10.3, p=0.01) points after the intervention.

**Conclusion:** Findings indicate that not only can fathers effectively learn important interventions for interacting and promoting social reciprocity skills in their children, they can also effectively train mothers to use these strategies. Also, there is evidence that mother-father differences exist. This suggests that training strategies may need to be tailored to reflect parental gender and roles. Clearly, there is an urgent need for more research as we endeavor to develop and implement the most effective treatment options for these most deserving families.

Judith A. Erlen, PhD, RN, FAAN; Susan M. Sereika, PhD; & Lisa K. Tamres, MS  
*University of Pittsburgh School of Nursing*

## **The Changing Profile of Patients with HIV**

### **Abstract**

**Aims:** Simplification of HIV medication regimens has increased longevity. HIV is a manageable chronic disorder. This study aims to examine the changing profile of HIV by comparing selected characteristics of two independent samples of HIV patients enrolled in clinical trials examining adherence to antiretroviral therapy between 1999 and 2009.

**Methods:** Using comparative statistics baseline data from 215 patients with HIV enrolled in clinical trial one (1999-2003) and 318 patients with HIV enrolled in clinical trial two (2004-2009) recruited from HIV clinics and through self-referral in western Pennsylvania and eastern Ohio were compared on selected demographic and disease related characteristics, adherence, and quality of life.

**Results:** The findings show that study 2 patients were older (43.4 years vs. 40.6 years), had a higher percentage of minority participants (55% vs 34%), and a higher level of unemployed or disabled persons ( $p < .001$ ). Samples did not differ on level of education or income. Primary exposure category for HIV was homosexual/bisexual for both samples, however study 2 had a higher proportion (52% vs 41%,  $p < .02$ ). Participants in study 2 had a higher frequency of missed clinic appointments (1.31 vs 0.73,  $p < .001$ ). General health subscale of a health-related quality of life scale (HR-QOL) was lower in study 2 (51.4 vs. 46.0,  $p = .015$ ). Viral load, CD4 counts, self-reported medication adherence, and other HR-QOL assessments were similar.

**Conclusions:** Patients with HIV were similar on relevant clinical measures though somewhat dissimilar on demographic characteristics. The changing face of HIV needs to be addressed in future clinical trials and practice.

**Anne L. Ersig, PhD, PNP-BC**

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## **Implications of Indeterminate Genetic Test Results**

### **Abstract**

**Background:** Indeterminate or inconclusive genetic test results are possible for many conditions. With expanded access to genetic testing, including wider use of genome-wide association studies (GWAS) and whole genome sequencing, more individuals will receive indeterminate genetic test results. Therefore, it becomes increasingly important to learn about how families share genetic and disease risk information when genetic test results are not clear-cut.

**Aims:** This study compared communication about genetics and risk between members of families with and without identified mutations for hereditary non-polyposis colorectal cancer (HNPCC).

**Methods:** Family communication networks of individuals who had genetic testing for HNPCC (n=20) and their first-degree relatives (n=31) were enumerated and described. Hierarchical nonlinear models were fitted to compare communication in families with and without identified HNPCC mutations.

**Results:** Members of families without identified HNPCC mutations shared thoughts about genetic testing and risk for HNPCC with a smaller proportion of network members, compared to members of families with identified mutations. Members of families without identified mutations were more likely to share thoughts about risk for HNPCC with network members whose advice they took, compared to members of families with identified mutations.

**Conclusions:** These findings highlight potentially important differences in communication of genetic risk information when genetic test results are indeterminate. Indeterminate or inconclusive genetic test results might hinder communication about genetic risk, or could lead to a need for additional clinical guidance. The implications of indeterminate or inconclusive genetic test results for health care decisions merit further examination.

**Jane M. Fall-Dickson, RN, PhD, AOCN**

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## **Predictors of Severe Infections in Chronic Graft-Versus-Host Disease**

### **Abstract**

**Aims:** Chronic graft-versus-host-disease (cGVHD) is a major complication of allogeneic hematopoietic stem cell transplantation (HSCT). Treatment of cGVHD with systemic immunosuppression is associated with significant risks for serious infection. This study examined prevalence and predictors of severe infections in patients with cGVHD. **Methods:** Retrospective analysis of 32 subjects enrolled in the National Cancer Institute (NCI) cGVHD Natural History Protocol (NHP) evaluated factors associated with first severe infection, defined per Cordonnier et al. (2006), after cGVHD diagnosis. A subset of 28 patients without first severe infection until NHP enrollment was evaluated to determine if Composite Severity Score (CSS), Clinical Global Rating (CGR), and laboratory parameters were associated with severe infection. Probability of developing severe infection was used to identify which factors jointly impacted development of severe infection probability after diagnosis. **Results:** Subjects (mean age =  $47.2 \pm 16.3$ ), were primarily male (53.1%), Caucasian (84%) and were a mean of  $9.9 \pm 14.7$  months from HSCT to cGVHD diagnosis. A majority had de novo (50%) or progressive (41%) cGVHD onset,  $2.4 \pm 1.8$  co-morbidities, mild (53%) or moderate (31%) cGVHD, and CSS mean score of  $27.9 \pm 10.5$ . Most prevalent infections included URI (25%), and pneumonia (12.5%). No factors appropriate for the Cox model were present in all patients. In 28 patients, the higher CSS, lower ANC, CMV recipient positive, donor Th2 cells, quiescent cGVHD, and more co-morbid conditions were associated with higher probability of severe infection. **Conclusions:** Restricting analysis to 28 patients identified factors jointly predictive of severe infection in a COX model. Further research in larger samples is warranted.

**Melissa Spezia Faulkner, DSN, RN, FAAN**  
*University of Arizona, College of Nursing*

## **PERSONALIZED EXERCISE: TEENS WITH DIABETES OR OBESITY**

### **Abstract**

Adolescents with diabetes or obesity have known cardiovascular risks and experience vulnerabilities due to increased weight and lack of exercise.

**Aim:** Our purpose was to determine the feasibility of a 16-week personalized exercise program (PEP) incorporating family support in home and community settings for adolescents with diabetes or obesity (age and gender-adjusted body mass index > 95<sup>th</sup> percentile).

**Methods:** Adolescents (N=35; 19, type 1 diabetes; 7, type 2 diabetes; 9, obese) had a mean age of  $14.4 \pm 1.6$  years (SD); 63% were Hispanic; 83% were Caucasian; 57% were female. Screening using the 7-day Physical Activity Recall ensured low levels of physical activity (PA), a daily mean of  $12 \pm 13$  minutes (SD) of moderate to vigorous PA (MVPA). The PEP was based on each adolescent's individual fitness level using a graded exercise test (i.e., VO<sub>2</sub>peak). An Actigraph™ Accelerometer was used to obtain PA adherence measurements.

**Results:** Adolescents wore the accelerometer for  $72 \pm 28$  days (SD), with the daily MVPA of  $43 \pm 22$  minutes (SD), a significant increase from screening levels [ $t(34)=8.89$ ,  $p<.001$ ]. On 72% of the days the accelerometer was worn, adolescents participated in 30 minutes of MVPA. On 40% of the days, they participated in 60 minutes of MVPA.

**Conclusions:** We determined that it is feasible to develop personalized exercise programs for these adolescents and to collect longitudinal PA data using accelerometers. Although adolescents were not yet meeting the current PA guidelines of 60 minutes of daily MVPA, exercise increased significantly over previous more sedentary behaviors.

**Mei R. FU**

*College of Nursing, New York University*

## **Proinflammatory Biomarkers and Post-Breast Cancer Lymphedema**

### **Abstract**

Lymphedema, a syndrome of abnormal swelling and multiple distressing symptoms, is a major adverse effect of breast cancer treatment, which can cause long-term physical, psychological, social, and financial problems. Besides cancer-treatment related risk, inflammation-infection and higher body mass index are the main predictors of lymphedema. Elevated levels of proinflammatory biomarkers have been speculated to be associated with lymphedema. Genetic variations may be one of the important factors that influence breast cancer survivors' responses to inflammatory processes and vulnerability to lymphedema.

The purpose of this exploratory project is to prospectively examine levels and patterns of proinflammatory biomarkers and genetic variations in relation to limb volume changes measured with the infra-red perometer-350S. A sample of 120 women who are newly diagnosed and treated for invasive breast cancer will be recruited. Data will be collected over a 12-month period, including: (1) measuring and comparing limb volume changes using the infra-red perometer, lymphedema symptoms, body mass index and body composition; (2) evaluating levels and patterns of proinflammatory biomarkers in relation to limb volume changes and lymphedema symptoms; and (3) evaluating genotypes known for inflammation in relation to limb volume changes and lymphedema symptoms.

This project is an important first step toward gaining necessary knowledge and insights into breast cancer survivors' susceptibility, which may help to identify survivors at higher risk based on individual survivors' biomarker patterns and genetic factors and potentially target the survivors at higher risk for more intense and personalized interventions to prevent and treat lymphedema.

**Ellen Giarelli**

*University of Pennsylvania, School of Nursing*

## **Genetic Correlates of Higher Cortical Function in Marfan Syndrome 1**

### **Abstract**

There is growing interest in uncovering the genetic determinants of neurocognition. In Marfan syndrome there appears to be a prevalence of learning and reading disabilities at a higher rate than in the general population. If this observation can be validated, it may be explained in two ways. First, there may be a pattern of co-inheritance of MFS and a separate genetic marker for neurocognitive disability. Second, neurocognitive problems observed in MFS may be part of the MFS phenotype. To determine the explanation for this phenomenon, we must first examine the co-occurrence of MFS and neurobehavioral problems and then examine the relationship between phenotypic and genotypic variability. The goal of this exploratory project is to examine neurocognitive problems among individuals with Marfan syndrome. Marfan syndrome, type I (MFS1) and type II (MFS2), are autosomal dominantly inherited disorders that occur in approximately 1 in 5,000 live births and show no sex or race biases. The disorders potentially affect numerous organ sites including: the bones, eyes, lungs, skin, CNS, and cardiovascular system. About 75% of cases are inherited and 25% are the result of a new germline mutation. MFS1 is caused by mutations in FBN1 which has been isolated to 15q21.1. Neurocognitive problems include learning disability [LD], attention deficit hyperactivity disorder [ADHD], and reading disability[RD]. The specific aims are to: determine the variability of neurocognitive problems among individuals with MFS 1; and identify DNA markers associated with LD, ADHD and RD among individuals with MFS1 as compared to MFS2 for the purpose of explaining variability.

**Susan W Groth, PhD, RN, WHNP-BC**

*University of Rochester, School of Nursing*

## **Limiting the Phenotypic Effects of Pregnancy Related Weight Gain: A Progress Report**

### **Abstract**

*Background:* Over 82% of African-American women are overweight/obese. Genetic susceptibility and individual behaviors likely interact to contribute to pregnancy weight gain and long-term obesity. The *GNB3* 825T allele is prevalent in the world-wide African-American population and has been associated with gestational weight gain, postpartum weight retention and infant birth weight.

*Objective/Aims:* Our aims are to examine the *GNB3* 825T allele gene-environment interaction during pregnancy and determine the physical activity essential to prevent excessive weight gain in women with the 825T allele. Results will be utilized to develop, test and implement interventions with African-American women to limit weight gain/retention.

*Methods/study population:* The study utilizes established self-report questionnaires, pedometers, weight/height measurements, resting energy expenditure measures, and DNA in adult African-American women. Data are collected at 5 time points across pregnancy and postpartum.

*Results:* Baseline data on the first 35 women enrolled: BMI range = 21-38 kg/m<sup>2</sup>; mean gestational weight gain is 34.5 pounds (SD = 20.9). DNA analysis will identify if there is a gene-environment interaction, and if so, targeted interventions will be developed to prevent excessive gestational weight gain. If there is no interaction effect, additional genes will be examined to determine obesity risk markers in pregnancy.

*Significance/impact:* This innovative project addresses primary prevention of obesity in African American women who are not yet obese but genetically predisposed to pregnancy weight gain. Many will face increased risk due to accumulation of weight with childbearing. A secondary outcome is identification of women at highest risk for delivery of low birth weight infants.



**Rebekah Hamilton PhD RN Associate Professor**  
*College of Nursing, Rush University*

## **Women, Children and Family Health Nursing**

### **Abstract—Genetics focus**

**Aims:** The purpose of this grounded theory investigation is to describe the complex array of issues individuals experience in their daily lives and the decisions faced following genetic testing for an adult onset disorder.

**Methods:** A grounded theory study with 44 young women with a BRCA mutation from 26 states and Canada between the ages of 18-39 years was completed in 2007. Interviews were conducted by phone or email based on the participant's preference. Email interviews, though more concise than phone interviews, provided sufficient material for in-depth analysis. Twenty one participants had already been diagnosed with breast cancer while 23 had not.

**Results:** Major categories of analysis included: 1) Shadows of family history, 2) Living with high risk, 3) Managing relationships, 4) Deciding on an action to follow, 5) Being strong.

**Conclusions:** Living with a positive BRCA mutation test result is challenging on many levels for young women. Experiences in their families colored their perception of risk even prior to genetic testing and this sense of personal risk was heightened after they received a positive BRCA mutation test result. Being young is a complicating factor in that they are no longer having similar experiences as their peers, nor do their health decisions seem age appropriate. Navigating the health care system and negotiating different opinions from different health care providers was a difficult and pervasive experience. Clinicians need to be aware of the multiple decisions young women with a BRCA mutation face and be knowledgeable of the recommended health care options.

**Kathleen M. Hanna, PhD, RN**  
*Indiana University School of Nursing*

## **TRANSITIONS AMONG LATE ADOLESCENTS WITH DIABETES**

### **Abstract**

**Aims:** Adolescents with diabetes are graduating from high school and moving out of their parents' homes. Parent-adolescent relationships, influential to diabetes outcomes, may change during these transitions, but little is known about these changes. This study examined changes in parent-adolescent relationships related to these transitions among late adolescents with type 1 diabetes.

**Methods:** A longitudinal study is in progress where late adolescents (17-21 years of age) with type 1 diabetes are being enrolled while high school seniors and living at home. The first cohort of 30 adolescents have completed baseline, 12- and 18-month data, via a web-based entry system, on diabetes-specific outcomes of Parental Over-involvement, Shared Responsibility, Support for Autonomy Development, Conflict, and Tangible Aid. We used a linear mixed effects model with months since graduation as the independent variable, treated as a continuous fixed effect to determine a slope in the parent-adolescent outcomes over time. We added whether or not they had moved from their parents' home by 12 months to examine interactions of move and time.

**Results:** Three parental relationship outcomes decreased significantly over time: over involvement (slope=-.09/month;  $p=.0017$ ), conflict (slope=-.27/month;  $p=.0088$ ) and tangible aid (slope=-.31/month;  $p=.002$ ). There were no statistically significant interactions of time and living situation.

**Conclusions:** Parental over involvement, conflict and tangible aid decreased over time; however, these changes did not interact with adolescents' move out of their parents' home. Examining changes in parent-adolescent relationships and their influence on diabetes outcomes in the larger study will provide data that can guide future transition interventions.

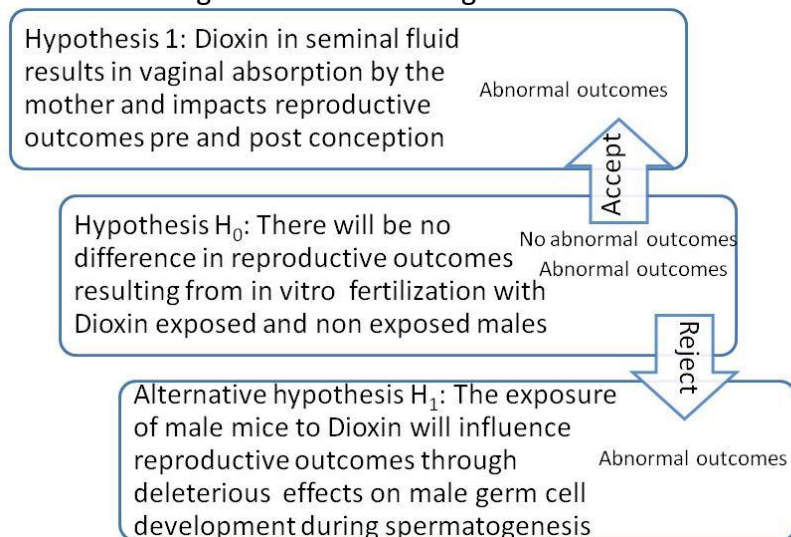
**Deborah A. Hansen, PhDc, RN<sup>1</sup> and Kelle Moley MD<sup>2</sup>**

<sup>1</sup> St. Louis VA Medical Center, University of Missouri – St. Louis; <sup>2</sup> Professor and Vice Chair, Department of Obstetrics and Gynecology, Division Director of Research, Washington University, St. Louis MO

## **Paternal Environmental Exposures and Reproductive Outcomes: A Comparison of in Vitro and in Vivo Fertilization**

### **Abstract**

**Objective:** The primary objective will characterize the effects of male dioxin exposure on selected parameters of natural mating as well as in vitro fertilization (IVF). Murine IVF circumvents female seminal fluid contact thereby separating the effect of vaginal absorption of toxins and the exposure of the embryo post conception from male germ cell effects. The secondary objective will determine if Dioxin exposure of male mice will influence reproductive outcomes through deleterious male germ cell effects.



**Design:** A 2 x 2 block design at T+14 and T+35 days post treatment will compare reproductive outcomes that result from in vivo vs. IVF of non exposed females with Dioxin exposed and non exposed males. An experimental repeated measures design corresponding to the stages of murine spermatogenesis (T + 6 days, T + 9 days, and T+14 days post treatment) will characterize the effects of dioxin exposure on male germ cell development.

**Materials and Methods:** 3.5 day post coitum (dpc) in vivo measures: a) blastocyst numbers, b) blastocyst TUNEL, CYP1A1, GLUT levels, and localization; c) blastocyst and stromal cell CYP1A1 RTqPCR, and d) stromal cell decidualization. In vivo and IVF parameters: a) 14.5 dpc placental and fetal weights, and crown to rump lengths; b) full term litter size, birth weights, and 5 week growth; and c) gross and microscopic structure. Laser microdissection (LMD), RTqPCR, and gene expression microarray will generate stage specific gene expression profiles in exposed and non exposed males.

**Results:** Optimization and validation of LMD protocols is underway. Data not yet available

**Kathleen T. Hickey EdD, FNP-BC, ANP-BC**

*Columbia University School of Nursing Assistant Professor of Nursing*

*Robert Wood Johnson Nurse Faculty Scholar*

## **The Impact of Cardiac Genetic Variants on Arrhythmia Susceptibility**

### **Abstract**

**Background:** Advances in cardiogenetics have provided insights into the genetic mutations that cause arrhythmias that can lead to sudden cardiac death (SCD). At-risk individuals undergo internal implantable cardioverter defibrillator (ICD) placement based on established guidelines, but generally without additional genetic information. An ideal population for investigation are individuals with a positive family history and diagnosis of a non-ischemic cardiomyopathy, such as dilated cardiomyopathy (DCM), hypertrophic cardiomyopathy (HCM), or restrictive cardiomyopathy (RCM), as well as those with underlying inherited arrhythmias such as long-QT syndrome, because most would not have had previous genetic testing to identify a molecular basis for their cardiac condition because the technology was not available at the time of their clinical diagnosis.

**Aims:** (1) To determine the prevalence, frequency and distribution of genetic mutations in genes associated with known cardiac disorders in individuals who have previously undergone an ICD implantation. (2) To correlate between the presence of a mutation, type of mutation, and gene affected, and the incidence of arrhythmias stored by the ICD.

**Methods:** 150 patients with a diagnosis of DCM, HCM, RCM, or long-QT syndrome, a positive family history, and a previously implanted ICD will be recruited for genetic evaluation. Individuals will undergo DNA testing to identify any underlying genetic basis for their diagnosis and correlate findings with (1) their prior clinical diagnosis and (2) arrhythmias recorded by their ICD.

**Implications:** If methods utilizing our advances in DNA technology could be coupled with our existing knowledge of clinical and diagnostic markers, then a more individualized approach to cardiac genetic testing and clinical care would be more widely available. Identification of those at highest risk for arrhythmias, such as other family members who harbor a genetic mutation and remain silently at risk for SCD, would also occur. This investigation is IRB approved and recruitment is ongoing at Columbia University. This proposal was initially developed as part of the Summer Genetics Institute (NINR) and is currently funded by the Robert Wood Johnson Foundation.

Chao-Pin Hsiao, PhD

## Relationship between Mitochondrial Dysfunction and Fatigue in Cancer Patients Receiving External Beam Radiation Therapy

### Abstract

**Background:** Over 40% of cancer patients receive modulated dose intensity radiation therapy during the management of their disease, which successfully increases survival rates and life expectancy but leads to increased treatment-related adverse effects including fatigue. While multidimensional mechanisms of cancer-related fatigue remain unclear, mitochondrial dysfunction is considered direct causes of radiation-induced damage.

**Objective:** To explore the relationship between mitochondrial dysfunction and fatigue in prostate cancer patients receiving external beam radiation therapy (EBRT).

**Methods:** Perceived fatigue and blood samples are collected at 7 time points. The Human Mitochondria RT2 Profiler™ PCR Array are utilized to identify differential regulation of genes involved in mitochondrial dysfunction and fatigue at the different time points compared to gene expression in the baseline samples.

**Results:** Mean perceived fatigue score was 1.52 (SD=1.91) at pre-radiation (baseline), increased to 2.79 (SD=2.02) at the midpoint of radiation therapy, and decreased to 2.60 (SD=2.33) by the end of radiation therapy, indicating increased fatigue at the midpoint and end of treatment. 6 genes with > 3 fold down-regulation among 2 of 4 patients compared to their baseline include *Bcl-2* [BCL2], *MGC111067* [MTX2], *HMIP/MIP* [MIPEP], *IMP1/IMP1-LIKE* [IMMP1L], *APC2/MCSC2* [SLC25A23], *DDP/DDP1* [TIMM8A]. One gene (*BCL-XL/S* [BCL2L1]) with > 3 fold up-regulation in 2 of 4 patients compared to their baseline.

**Conclusion:** Potential findings of gene expression associated with mitochondrial function may identify possible pathways and early biomarkers of radiation-induced fatigue. Further studies exploring and validating biomarkers of mitochondrial dysfunction causing cancer-related fatigue will be necessary to identify novel interventional targets for this population.

**Christopher C. Imes, BSN, RN, Doctoral Student**  
University of Washington, School of Nursing

## **A Family History Based Intervention to Increase Perceived CVD Risk**

### **Abstract**

**Problem:** Approximately 81 million Americans have one or more forms of cardiovascular disease (CVD) and, in 2006, CVD accounted for 34.3% of all deaths in the United States. Although most forms of CVD manifest symptoms in middle age, the behavioral risk factors take hold much earlier. Personal habits, including diet, exercise and smoking, can either increase or decrease an individual's risk for developing CVD.

**Purpose:** The epidemiologic evidence for the familial aggregation of CVD is well established and family history is an independent risk factor for CVD. Therefore, family history can be used as a screening tool to identify individuals, especially asymptomatic young adults, at increased CVD risk. Additionally, a family history intervention that increases perceived CVD risk has the potential to impact health promoting behaviors. In a single group, pre-test post-test pilot study, a family history based intervention in young adults consisting of constructing a three-generation pedigree and providing CVD risk counseling will be tested.

### **Primary Aims:**

Aim 1: To explore the relationship between a family history of CVD, perceived CVD risk, and behavioral intent towards health promoting behaviors.

Aim 2: To test the short-term impact of a family history of CVD on perceived CVD risk.

Aim 3: To examine if the amount and quality of family history information will increase after young adults have the opportunity to discuss their family history with their relatives.

**Relevance:** This study will advance our knowledge of how young adults understand a family history of CVD and how this impacts perceived CVD risk.

**Jillian Inouye, PhD, APRN**

*University of Hawaii at Manoa, School of Nursing and Dental Hygiene*

**Center for 'Ohana and Self-Management in Chronic Illnesses in Asian/Pacific Islanders (COSMCI)**

**Abstract**

**Introduction:** Self-management involves many lifestyle decisions and behavioral adaptations.

For Asian/Pacific Islanders (API) some behaviors are counter to their cultural practices and beliefs; as the family, extended family, and significant others are regularly involved in a person's care. Individualized treatment plans and self-management are prominent values in Western cultures while Eastern and Native Hawaiian approaches incorporate the group; reflecting collectivistic values. The Hawaiian term *'ohana* originally referred to the family clan or extended family and now extends to non-related family members. This inclusivity and collectivism relies on consensus decision making and collaboration, while maintaining hierarchical relationships with health care providers. As chronic illnesses are experienced within the *'ohana*, this Center's purpose is to focus on factors that can help understand self and *'ohana*-management.

**The aims:** 1) create an environment conducive to interdisciplinary *'ohana* self-management of chronic illness research in ethnically diverse populations; 2) develop sustainable interdisciplinary, biobehavioral research capacity; 3) disseminate and translate knowledge generated; and 4) evaluate activities and outcomes.

**Methodology:** Projects include: 1) Self-efficacy and Self-Management for Persons with Symptomatic HIV disease; 2) Kalusagan ay Kayamanan (health is wealth) Type 2 Diabetes Prevention in Filipinos; 3) A Breathing Pattern Retraining Self-Management Intervention with an Interactive Telecommunication System for Persons with COPD; 4) End-of-Life Decision-Making Among API Caregivers of Family Members on Hemodialysis; and 5) Psychosocial and Cultural Values Related to Dietary and Physical Activity Practices of APIs with Type 2 Diabetes.

**Summary:** These multi-disciplinary studies will contribute to the science of interventions and health outcomes for APIs.

**Yun Jiang**

*University of Pittsburgh School of Nursing*

## **A STUDY OF AFTER-HOURS CALLS IN HOSPICE PATIENT CARE**

### **Abstract**

**Aims:** Few studies have reported on after-hours calls in hospice patient care. This retrospective study examines utilization of after-hours triage services by hospice and palliative care patients and their family caregivers.

**Methods:** Using a fixed coding scheme for descriptive analysis, two trained research staff members coded a random sample of calls (n=442) from the after-hours triage phone log of all calls between July 2005 and June 2006 (n=4418) from a Pennsylvania hospice and palliative care services agency. Descriptive statistics were used to: 1) identify timing and reasons for utilization by patients and caregivers and 2) describe predominant nursing interventions offered.

**Results:** Approximately two-thirds of calls occurred on weekdays (69.1%), one-third on weekends (30.9%). Half of all calls took place within 4 days of the patient's death. The top five uses for triage services were to request a home visit or report new signs and symptoms (42.6%), inquire about medications (17.9%), report death (13.8%), seek admission, discharge, or referral information (8.9%), or seek emotional or logistical support (4.1%). The top five nursing interventions included updating case managers on their patients' status (27.1%) or needing a follow-up (24.4%), instructing how to control new signs and symptoms (11.7%) or resolving medication-related problems (8.2%), and coordinating home visits (7.8%).

**Conclusions:** A greater understanding of the timing and reason for the use of triage services can assist in the design of proactive interventions to improve care for families and patients and can enhance training for new and existing hospice triage nurses.



**Lesly A. Kelly, PhD, RN**

*Postdoctoral Research Fellow Center for Health Outcomes and Policy Research  
University of Pennsylvania School of Nursing*

## **Workforce Factors, Nurse Outcomes, and the Quality of Care**

### **Abstract**

**Aims:** To examine the effects of staffing and the practice environment on nurse outcomes and nurse-rated quality of care.

**Methods:** A secondary analysis of 2006 survey data from a random sample of 20,308 registered nurses working in 604 hospitals in California, Florida, New Jersey, and Pennsylvania. Nurses were queried on demographics, the work environment, job-related outcomes, and the quality of care. The work environment and job-related burnout were assessed using the Practice Environment Scale of the Nursing Work Index and the Maslach Burnout Inventory. Single items assessed job dissatisfaction and quality of care.

**Results:** Workload and the practice environment significantly predicted job dissatisfaction, burnout, and nurse-rated quality of care. With an average 4.9 patients per nurse, each additional patient added to the nurse's workload was associated with an increase in job dissatisfaction (12%) and in job-related burnout (8%). Increased workload was also associated with a 19% increase in the likelihood of nurse's rating the quality of care on their unit as fair or poor. Improvement in the practice environment was associated with decreases in job dissatisfaction (29%) and burnout (20%). Improved environment was also associated with a 39% decrease in the odds of quality of care being rated as fair or poor.

**Conclusions:** The deleterious effects of increasing nurse workload are well known and continue to be demonstrated in this study. The nurse work environment has potential to improve the quality of care through increased job satisfaction and decreased job-related burnout at little or no cost to health care facilities.

**Kim H, Baek S, Kim M, Kerr M, Dionne R, Schneider M, Lincz L, Poloyac S, Park J**

*NINR/NIH, University of Ulm, New Castle Hospital, University of Pittsburgh, Korea University*

## **Advanced Genome Wide Approaches in Nursing Research**

### **Abstract**

Personalized health care is defined as the application of genomic and molecular data to help determine a person's predisposition to a particular disease or condition, better target the delivery of therapeutic strategies, and facilitate the discovery of new products. The purpose of our program of research is to integrate genetic variations, gene expression profiles and epigenetic findings to determine their influence on individual responses to disease conditions or therapies, at the entire genome wide level, so that we can achieve our ultimate goal of individualizing therapy based on the patients molecular-genetic profile. Despite important contributions for the last few decades, investigation on candidate regions from human genome has limitations, mainly caused by the lack of complete knowledge of human genome. To overcome this limitation of candidate gene approaches, we apply genome wide approaches using microarray based platforms and next generation sequencing technology. Currently 3 projects of genome wide association studies are on-going with Affymetrix microarray platform in the intramural laboratory of NINR. Samples from hundreds to thousands of patients with fibromyalgia, acute coronary syndrome and subarachnoid hemorrhage were collected and are being genotyped. In addition, we are sequencing the entire genome from a capsaicin insensitive patient and a sibling control using the next generation sequencer, Illumina Genome Analyzer IIx. This presentation will provide an overview and preliminary results of these on-going projects based on genome wide approaches.

**Deborah Koniak-Griffin, RNC, EdD, FAAN**  
*UCLA School of Nursing*

### **Building Nursing Science to Eliminate Health Disparities in Vulnerable Populations**

#### **Abstract**

The Center for Vulnerable Populations Research (CVPR), established in 1999 as a center of nursing excellence, is advancing nursing science in the area of community-based participatory research (CBPR) and health disparities (HD) in vulnerable populations (VPs). Although a number of VPs exist, focus has been placed on ethnic/racial minorities, the poor and marginalized groups such as the homeless and substance users. Through community-academic partnerships, many CVPR investigators are enhancing understanding about HDs and developing strategies to eliminate them. Areas of emphasis include infectious diseases such as HIV/AIDS, TB and hepatitis and chronic illnesses (e.g., heart disease). Additionally, risk factors (e.g., violence, obesity) contributing to health disparities are examined. During the past decade, the Center has supported over 30 pilot studies conducted by School of Nursing faculty, interdisciplinary colleagues and community partners. About 25% of the PIs of pilot studies have obtained external funding for research related to their CVPR grant. Investigators in the research base are continuing to secure federal funding for their program of HD research. A variety of dissemination modalities are used to advance knowledge about CBPR and HDs, including state-of-the-science texts and publications, and educational activities. One of the hallmarks of the CVPR is its annual Summer Institute on CBPR to eliminate HDs. Graduates of the Summer Institute are conducting HDs research and scholarship that similarly contributes to the field.

**Elizabeth A. Kostas-Polston, PhD, RN, WHNP-BC**

*Assistant Professor of Nursing, Saint Louis University; NIH Fellow, NINR Summer Genetics Institute 2009*

## **AN INVESTIGATION OF THE EFFECTIVENESS OF MOLECULAR ASSAYS AND SAMPLING METHODS FOR THE DETECTION OF OROPHARYNGEAL HPV**

### **Abstract**

Human papillomavirus (HPV) is the most common sexually transmitted infection in the United States. HPV is a principal source of cancer that occurs in the oropharynx. While the overall incidence of head and neck cancer is steadily decreasing, the overall incidence in oropharyngeal (OP) cancer is increasing. Of clinical significance is HPV genome 16, quickly becoming one of the leading causes of OP cancer in women with a history of cervical cancer, and accounting for up to 95% of all HPV-positive, OP tumors in men. The notion of the detection of OP-HPV, for the most part, is unexplored. The proposed project is a prospective, pilot study which is unique in that the effectiveness of molecular and cytologic assays and sampling methods for the detection of HPV infection will be investigated. In light of the HPV epidemic and the increasing incidence in HPV-related OP cancer, identifying a screening test to detect HPV in the oropharynx is critical. The aims of this study are to: a) identify differences in the sensitivity, specificity, and positive and negative predictive values across molecular and cytologic assays, and sampling methods, b) explore how well molecular and cytologic assays predict the presence of HPV infection in the oropharynx, and c) use the data generated from this pilot study to design a larger, adequately powered study for further investigation into a screening test for detection of HPV infection in the oropharynx.

**Eileen T. Lake, Ann Kutney-Lee, Lesly Kelly & Linda H. Aiken**  
*University of Pennsylvania School of Nursing*

## **Center for Nursing Outcomes Research: Documenting the Impact of Nursing Care**

### **Abstract**

For the past 10 years, the Center for Nursing Outcomes Research (CNOR) has been a key component of the Center for Health Outcomes and Policy Research (CHOPR), one of 6 research centers at the University of Pennsylvania School of Nursing. CNOR uses science to build the infrastructure to connect nursing communities with their government and policymakers. Our activities to sustain health care outcomes research focus on tracking developments in healthcare and the nursing workforce internationally, as well as pursuing the newest methodological approaches and available datasets to expand the program into areas that respond to changing health needs and workforce demands. CNOR pursues scientific evaluation of changes in healthcare legislation, such as the California hospital nurse staffing mandates, as well as translational research. The CNOR and CHOPR have developed extensive research collaborations in the U.S. and in dozens of countries and have completed the first outcomes research of its type in many countries. CNOR remains the leader in outcomes research methodology. Innovative research designs, sampling approaches, large scale surveys of nurses, web-based data collection, the strategic merger of multiple, complex data sets, measure development, geocoding technology, and sophisticated multilevel statistical analysis are our hallmarks. Dissemination is wide-ranging, and includes scholarly works, print, web & broadcast media, and numerous speaking engagements.

**Laura E. Kwako**

*National Institute of Nursing Research, National Institutes of Health*

**Major Depressive Disorder in Persons Exposed to Traumatic Events: Comparisons among Emotional Intelligence and Perceived Social Support**

**Abstract**

Traumatic events are often linked to the onset major depressive disorder (MDD), as well increased risk for non-remittance of symptoms; however, psychological factors that may contribute to the relationship between trauma and chronic depression are not well-defined. The present study examines two psychosocial factors that may contribute to chronic depression in trauma survivors, emotional intelligence (EI) and social support. Participants who experienced a trauma and had current MDD ( $n = 38$ ), were compared to non-traumatized healthy controls ( $n = 40$ ). Traumatized depressed participants exhibited lower strategic EI ability and reported lower levels of social support compared to non-traumatized healthy controls. EI and social support were significantly correlated. These findings suggest that EI abilities may be a novel target for therapeutic intervention to prevent MDD onset as well as to treat chronic MDD.

**Gwen Latendresse, PhD CNM**  
*University of Utah College of Nursing*

## **Epigenetics and Gene Expression in Preterm Birth**

### **Abstract**

It is well established that spontaneous preterm birth has a multifactorial etiology, much like hypertension and type II diabetes mellitus. Furthermore, several studies implicate a polygenic contribution to preterm birth by identifying significant associations with multiple genetic polymorphisms linked to plausible biological pathways (i.e. inflammation and coagulation). More recently, the influence of environmental conditions on the maternal epigenome has become of considerable interest to researchers, epidemiologists, health policy makers, and health care providers alike. The premise that the epigenome has equal relevance to pregnancy outcomes as does DNA nucleotide sequencing, hinges on the fact that it is gene expression that ultimately directs cellular function. Furthermore, gene expression (activation and “silencing”) can be greatly influenced by the epigenetic biochemical remodeling of chromatin, i.e. methylation and acetylation. Moreover, these biochemical modifications can be enduring, thus multigenerational, and may be initiated by environmental factors, such as pollutants, nutrients, stress mediators, and cellular communicators (i.e. cytokines and hormones). There is considerable speculation on the epigenetic contribution to pregnancy outcomes, such as preterm birth.

This poster presentation will focus on the genetic and epigenetic contributions to the preterm birth phenotype, including how variations in gene expression can be identified along the four identified pathophysiologic pathways to preterm birth. Implications for reproductive families will also be noted.

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**Sherrie G. Lessans, PhD, RN**

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## **BDNF Modulates Paclitaxel-induced Mechanical Allodynia**

### **Abstract**

Paclitaxel treatment is associated with significant peripheral sensory dysfunction and pain which can lead to early termination of treatment, persistent neuropathies resistant to conventional approaches to symptom management, and reductions in quality of life for cancer survivors. Brain-Derived Neurotrophic factor (BDNF) is up-regulated in several neuropathic pain conditions but has not been examined as a potential mechanism or treatment target in paclitaxel-induced pain. The aim of this study was to explore the nociceptive role of BDNF in a mouse model of paclitaxel-induced pain, with a focus on the expression of BDNF and its receptor trkB in the spinal cord. Adult male mice were randomly assigned to receive either paclitaxel resuspended in cremophor (4 mg/kg) or cremophor alone. Mechanical allodynia was assessed on days 4, 7, 11, 14, and 21. Reducing BDNF levels in the dorsal horn via genetic manipulation of BDNF expression reduced allodynia but did not alter symptom trajectory. Targeted reductions of BDNF using an intrathecal BDNF scavenging protein reduced both allodynia development and symptom trajectory. Genetic deletion of the truncated trkB.T1 receptor, a dominant-negative inhibitor of BDNF signaling, resulted in almost complete attenuation of paclitaxel induced allodynia, while blockade of full-length trkB signaling modulated both the induction and the persistence of PPN. Results suggest that reducing levels of spinal BDNF early in the course of treatment may blunt both the severity and persistence of PPN, while therapies targeted at the truncated T1 isoform of the trkB receptor may reduce or prevent symptom onset.



**Susan J. Loeb\*, Janice Penrod\*, Christopher S. Hollenbeak†, Carol Smith\*, and Pamela Spigelmyer\***

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The Pennsylvania State University*

## **Identifying and Prioritizing End-of-Life Care Needs: The Prison Study**

### **Abstract**

**Background:** Prisons are complex, restrictive organizations that care for highly vulnerable individuals, some of whom are living with and dying from chronic illnesses. Good science exists on *what* to do in terms of end-of-life (EOL) care—but infusion of this knowledge into complex organizations remains problematic.

**Purpose:** To compare and contrast the status of EOL care in contextually diverse prisons and to describe components of an intervention toolkit for enhancing EOL care, which is responsive to the prioritized needs identified by key informants.

**Methods:** Using Participatory Action Research, Nursing and Health Economics researchers are collaborating with key informants from state prisons to plan, assess, act, and observe transformations in current organizational practices pertaining to EOL care. Co-ownership of the research process and outcomes is critical and will facilitate the translation of research findings toward enhancing supportive EOL care in prisons.

**Findings:** Common themes, such as *Characteristics of a Good Death*, permeated the values, beliefs, and perceptions of system-wide needs regarding EOL care expressed by the staff at six distinct state prisons. Numerous barriers to delivering high quality EOL care in prisons were cited, including *Maintaining a Balance* between security and caring. However, some EOL practices were described as, “I think we do...a pretty good job with it within all the constraints.”

**Conclusions:** Improving EOL care for inmates who are suffering from advanced chronic illnesses will lay the crucial groundwork needed for future research aimed at infusing generalist EOL strategies into other complex organizations.

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### ***Symptoms in Patients with CHB Treated with Nucleos(t)ide Analogue Therapy***

#### **Abstract**

**AIM:** To prospectively evaluate the effect of nucleos(t)ide analogue therapy on symptoms in patients with chronic hepatitis B(CHB).

**METHODS:** 41 patients randomized to receive lamivudine(LAM) and adefovir(ADV)( $n=22$ ) or ADV( $n=19$ ) for 4 years. A visual analog symptom questionnaire was administered at each study visit. Data from 8 symptoms and overall well-being were analyzed at baseline, years 1 and 4. Data from patients with HBsAg loss or treatment failure before year 4 were censored and carried forward to year 4.

**RESULTS:** Mean age 46.2(range 22-77), 82.9% male, 42% White, 46% Asian, 12% Black and 76% HBV e antigen positive. Ninety-five percent( $n=39$ ) reported one or more symptoms at baseline. Patients reported feeling significantly better overall( $p=.032$ ) after 1 and 4 years( $p=.007$ ) of either treatment. There were no significant differences in reported symptoms at year 1 between the 2 groups except more significant nausea( $p=.006$ ) in the ADV group. At year 4 there were significantly higher symptoms in the ADV group for (fatigue,  $p<.001$ ; muscle ache,  $p=.029$ ; irritability,  $p=.021$ ; depression/sadness,  $p=.015$ ; overall well-being,  $p=.003$ ). Non-responders had significantly greater symptoms (fatigue,  $p=.008$ ; nausea,  $p=.026$ ; poor appetite,  $p=.013$ ; headaches,  $p=.014$ ; itching,  $p=.035$ ; worse overall well-being,  $p=.029$ ). Baseline albumin correlated with fatigue( $r=.381$ ), muscle aches( $r=.375$ ), and overall well-being( $r=.355$ ) but there was poor to no correlation( $r<.320$ ) between baseline symptom scores and clinical markers of disease severity.

**Mary S. McCarthy, RN, PhD**

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## **Characterizing Nutrient-Gene Expression and Adaptive Immunity in Cancer**

### **Abstract**

**Background:** Cancer is characterized by T cell dysfunction, increased production of cytokines, and decreased expression of the T cell receptor due to a loss of the CD3 zeta chain peptide. Arginine, a conditionally-essential amino acid, is critical to T lymphocyte function and proliferation and ultimately, immune system activation. Identifying cancer patients with low arginine states will lend support for early intervention with immune-modulating nutrition containing L-arginine.

**Aim:** The primary aim of this study is to describe the manifestation of arginine deficiency in head and neck cancer (HNCA) patients.

**Design:** A prospective, comparative, two-group design is being utilized.

**Sample:** Convenience sample of surgical HNCA patients and healthy controls presenting for evaluation at a military medical center.

**Methods:** 20 subjects will provide blood specimens during three hospital/post-operative visits. Biomarker levels of arginase I and iNOS will be measured using reverse-transcriptase RT-PCR. T cell function, T cell receptor CD3 $\zeta$  chain expression, and nitrite and nitrate plasma samples will be analyzed with flow cytometry and HPLC, respectively.

**Data analysis:** Repeated measures ANOVA will be used to compare biomarker results at baseline, 7 days, and 30 days following surgery.

**Findings:** Preliminary results will be available in September.

**Conclusions:** Results will be used to develop an RCT in the HNCA population which will inform nutrition therapy protocols designed to provide personalized, targeted support to achieve optimal clinical outcomes for patients with HNCA.

**Implications:** The evolving science of nutrigenomics will help nurses understand better how nutrients affect gene expression with implications for long-term health of the individual.

**Jean C. McSweeney, PhD, RN, FAHA, FAAN**

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***Research Center for Individualized Nursing Interventions***

**Abstract**

**Purpose:** The University of Arkansas for Medical Sciences (UAMS) College of Nursing (CON) established the **Research Center for Individualized Nursing Interventions, named the Tailored Biobehavioral Interventions Research Center (TBIRC)**, to bring together a cadre of scientists to facilitate and enhance the development of the science of individualized nursing interventions and inform clinical practice. **Structure:** The Center is composed of 2 Cores: the **Administrative Core**, which facilitates research on individualized nursing interventions, and the **Pilot/Feasibility Studies Core**, which educates and mentors the Center's Pilot Investigators and Faculty Scholars in conducting research on individualized nursing interventions. **Funding:** TBIRC has funded 19 one-year pilot studies and 3 Faculty Scholars (25% effort). **Outcomes:** The TBIRC Core and Pilot Investigators have discovered scientific evidence for individualized interventions; developed, refined, and published a conceptual model to guide research; and published a manuscript on developing and testing tailored interventions based on the TBIRC Model. In the 6 years since obtaining NINR funding, the TBIRC Pilot investigators have received over \$11 million in additional extramural funding. We also developed a database of over 1000 scientific articles related to tailoring and testing interventions. The Pilot Investigators, Faculty Scholars, and Core Directors have conducted and disseminated relevant clinical research on individualized nursing interventions resulting in over 50 papers or posters presented from local to international conferences and 15 manuscripts published. The TBIRC-supported research has made a significant impact on improving the health and well-being of people across the lifespan.

**John Merriman, RN, AOCNS**

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## **Preliminary Evidence of a Genetic Association Between an *IL6* Promoter Polymorphism and the Severity of Self-Reported Attentional Fatigue**

### **Abstract**

**AUTHORS:** John D. Merriman, RN, MS<sup>1</sup>; Bradley E. Aouizerat, PhD<sup>1,2</sup>; Marilyn Dodd, RN, PhD<sup>1</sup>; Kathryn Lee, RN, PhD<sup>1</sup>; Claudia West, RN, MS<sup>1</sup>; Steven M. Paul, PhD<sup>1</sup>; Bruce A. Cooper, PhD<sup>1</sup>; Patrick S. Swift, MD<sup>4</sup>; William Wara, MD<sup>5</sup>; Laura Dunn, MD<sup>3</sup>; Christine Miaskowski, RN, PhD<sup>1</sup>

**INSTITUTIONAL AFFILIATIONS:** School of Nursing<sup>1</sup>, Institute for Human Genetics<sup>2</sup>, School of Medicine<sup>3</sup>, University of California, San Francisco; Alta Bates Comprehensive Cancer Center, Berkeley, California<sup>4</sup>; Kaiser Permanente, San Francisco<sup>5</sup>. This study was supported by T32 (NR07088) and R01 (NR04835) grants funded by the National Institute of Nursing Research. Additional support was provided by the American Cancer Society Doctoral Degree Scholarship in Cancer Nursing (DSCN-10-087).

**SIGNIFICANCE:** Purposeful concentration during demanding situations results in attentional fatigue. This symptom is experienced as decreased ability to concentrate and maintain purposeful activity.

**PURPOSE:** The purposes of this study were to identify latent classes of attentional fatigue and determine the relationship between the *IL6* -572C>G (rs1800796) promoter polymorphism and these classes.

**METHODS:** Attentional fatigue was evaluated in 242 patients and family caregivers using the Attentional Function Index before radiation therapy and at additional assessments over six months. Growth mixture modeling was used to identify latent classes of participants with distinct trajectories of attentional fatigue. Using a dominant model (CC versus CG+GG), a chi-square test was used to evaluate for differences in genotype frequency between the classes.

**FINDINGS/IMPLICATIONS:** Two classes of participants with distinct trajectories of attentional fatigue were identified: low attentional fatigue (62.8%) and moderate attentional fatigue (37.2%). Participants in the moderate group were younger, had more comorbidities, reported more symptoms of anxiety and depression, and had more sleep disturbance and physical fatigue. They were also more likely to carry the minor G allele ( $p=0.013$ ) (MAF=9.5%). This provides preliminary evidence of distinct groups of oncology patients and family caregivers who experience different levels of attentional fatigue over the course of radiation therapy. In addition, this provides preliminary evidence of a genetic association between *IL6* and the severity of attentional fatigue. Future studies should confirm these latent classes and the effects of -572C>G so that this and other genomic markers could be used to identify persons at risk for attentional fatigue.

**Elizabeth I. Merwin**

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## **Engaging Communities in Rural Health Care Research**

### **Abstract**

Geographic health disparities faced by rural populations will be presented and strategies for engaging relevant stakeholders to overcome these disparities and to improve rural health care outcomes and the health status of rural populations will be identified. The Rural Health Care Research Center (RHCRC), an interdisciplinary research center located in the University of Virginia School of Nursing, was begun with funding from the National Institutes of Health/National Institute of Nursing Research in 2004 and has conducted 15 pilot studies since that time. The center has a commitment to community participation research and to engagement of community partners. Conferences, workshops, and presentations the center has focused on building partnerships with community partners and investigators from across the university. Some of the different approaches that have been used in center pilot studies and in other rural studies to conduct community research will be highlighted and will be used to need future research. Integrating results from different study approaches and from community leaders experiences will inform proposed strategies to use in health care research to improve rural health care.

**Norma A. Metheny, RN, PhD, FAAN**  
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## **Gastrointestinal Indicators of Risk for Aspiration**

### **Abstract**

**Aims:** To determine the association between aspiration and three presumed indicators of gastrointestinal tolerance to tube feedings.

**Methods:** A total of 498 critically ill, mechanically ventilated tube-fed patients were followed prospectively over three consecutive days. Data collectors were present 16 hours each day to assess bowel sounds, measure residual volumes from feeding tubes, and record the incidence of vomiting. Suctioned tracheal secretions were assayed in a research laboratory for the gastric enzyme, pepsin (a proxy for aspiration). Patients were categorized as being frequent aspirators if  $\geq 25\%$  of their tracheal secretions tested positive for pepsin; those with  $< 25\%$  pepsin-positive secretions were categorized as infrequent aspirators. Bowel sounds were dichotomized as hypoactive at least once or never hypoactive. Feeding tube residual volumes were categorized as  $\geq 100$  ml at least once, or never as high as 100 ml. Vomiting was coded as having occurred at least once, or never present. Chi square analyses were performed.

**Results:** Forty-five percent of the patients were in the frequent aspirator group. No significant difference was found in the incidence of hypoactive bowel sounds between the two aspiration groups. However, frequent aspirators were significantly more likely than infrequent aspirators to have at least one feeding tube residual volume  $\geq 100$  ml (32.4% versus 16.5%, respectively,  $p < .001$ ). Similarly, vomiting occurred significantly more often in the frequent aspirator group (9.3% versus 3.3%, respectively,  $p = .005$ ).

**Conclusions:** A feeding tube residual volume  $\geq 100$  ml and vomiting are reasonable indicators of risk for aspiration.

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## **STRUCTURAL AND FUNCTIONAL EVALUATION OF BRANCHED MYOFIBERS IN MDX MICE**

### **Abstract**

In patients with Duchenne's muscular dystrophy (DMD), malformed myofibers are thought to increase susceptibility to activity dependent muscle damage; however the basis for these malformations and their impact on muscle function is not fully understood.

**Aims:** Assess the structure and excitation contraction (EC) Coupling function of malformed fibers in the murine model of DMD (i.e., *mdx*). Use the Diffusion Tensor Imaging (DTI) MRI technique to examine myofiber architecture of intact *mdx* and control muscles *in vivo*.

**Methods:** The occurrence, morphology, and function of malformed myofibers were examined in isolated *mdx* and age-matched control mice. Osmotic challenge was used to indirectly measure membrane stress susceptibility.  $\text{Ca}^{2+}$  transient analysis was used to evaluate EC coupling. High resolution T1-weighted, multi-echo T2-weighted, and spin echo diffusion tensor (to noninvasively track myofibers) MR images were acquired (7T Bruker Biospec).

**Results:** In *mdx* muscle examined *in vitro*, visible malformations occurred in 6% and 65% of myofibers in young and old mice, respectively. Despite these malformations, cytoskeletal architecture appeared normal. Age-matched controls did not display altered morphology. Further, malformed myofibers exhibited decrements in electrically evoked  $\text{Ca}^{2+}$  release and increased stress dependent  $\text{Ca}^{2+}$  dysregulation indicating compromised function. Using the DTI-MRI technique, gross myofiber morphology was differentiated in *mdx* muscle prior to, and after experimentally induced injury.

**Conclusions:** In the *mdx* muscle, malformed myofibers exhibit a functional phenotype consistent with decreased function and enhanced damage susceptibility. DTI imaging may provide a critical non-invasive measure of myofiber morphology to aid in monitoring disease progression and outcomes from current therapeutic intervention.



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## **The FIND Lab: Full INclusion of Persons with Disabilities in Self-Management Research.**

### **Abstract**

**Aim:** To develop a framework for fuller inclusion of people with disabilities in mainstream research.

**Methods:** Inclusion of people with disabilities in research is both scientifically sound and ethically necessary. Funded by an NIH grant, we adapted “Principles of Universal Design” (originally developed for architecture) and “Universal Design for Learning” (originally developed for teaching all students effectively in regular classrooms), to produce a framework for promoting inclusion of people with visual and hearing disabilities in research. Using this framework, we collaborated with disability rehabilitation professionals to produce specific recommendations for researchers.

**Results:** A framework for inclusion of people with disabilities in mainstream research involves providing multiple ways for participants to (1) learn about the research; (2) arrive at the research site; (3) access research instruments and interventions; and (4) respond to research instruments and interventions. For example, research instruments and interventions can be presented in a variety of formats: large print, audio-enabled touch-screen computers, American Sign Language, interpreters, Braille, audio recording, or audio-described videotapes. Research procedures can be adapted by distributing recruitment notices through both visual and auditory media (e.g., posters and radio); research sites can be planned to be convenient to non-drivers or transportation provided for non-drivers. We are building demonstration models of research applications using our framework for inclusion.

**Conclusions:** Including people with visual and hearing disabilities in research is neither difficult nor expensive. Investigators can learn techniques to adapt current research methods for inclusion of people with disabilities, thus increasing the generalizability and relevance of research findings.

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## **IL-6 AND TNF- $\alpha$ GENE POLYMORPHISMS, CACHEXIA, AND DEPRESSION IN CHRONIC HEART FAILURE**

### **Abstract**

**OBJECTIVES:** To identify genetic variation in genes that may affect depression and its influence on cardiac cachexia (CC) in patients with chronic heart failure (CHF), and examine the relationship of CC with inflammatory gene variants and depression.

**BACKGROUND:** Depression and CC are both associated with disease progression through activation of sympathetic and inflammatory mechanisms. However, genetic mechanisms that link the two conditions are poorly understood.

**METHODS:** One hundred sixty CHF patients are conveniently recruited and weight loss of  $\geq 6\%$  over  $> 6$  months is used to identify cachectic patients. Anthropometric measures, 3-Day Food Record, Patient Health Questionnaire-9, and serum IL-6 and TNF- $\alpha$  are collected at baseline and at 6 months. Blood samples for analysis of TNF- $\alpha$ -308 G/A, IL-6-174 G/C, and IL-6-634C/G single nucleotide polymorphisms (SNPs) are collected at baseline. Student's t-test,  $\chi^2$ , multivariate linear and logistic regression analyses are used to compare groups and to examine genotype associations with CC and depression.

**IMPLICATIONS:** The proposed study is the first to examine the relationships between CC, depression, inflammation, and genetic predisposition in patients with CHF. The significance of this proposal is to advance the understanding of the effect of genetic vulnerability for CC and depression and help elucidate biological pathways common to both syndromes, particularly those involved in inflammation. Identification of genetic contributions to CC and depression may provide more precise assessment of risk while identifying explanatory pathways in individual patients, reveal new targets for intervention, and ultimately enable individually-tailored approach to care.

**Carol Musil, Nahida Gordon, Camille Warner, Jaclene Zauszniewski, Theresa Standing and May Wykle**

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## **Grandmothers as caregivers: Findings and Directions**

### **Abstract**

**Aims:** Transitions in caregiving to grandchildren, such as becoming a primary caregiver to grandchildren or having grandchildren and their parents move in or out of the grandmother's home, may impact the well-being of the grandmother. The purpose of this study was to examine the effects of stability and change in caregiving to grandchildren.

**Methods:** Data were collected by mailed survey at three time points, approximately one year apart, from 485 Ohio grandmothers. Drawing on the Resiliency Model of Family Stress, we examined caregiving stress and reward, intra-family strain, support, resourcefulness, mental and physical health, and perceived family functioning. Caregiver group, time of measurement, switching between caregiver groups, and baseline age, race, education, employment and marital status were included within the context of a one-way treatment structure in an incomplete block design.

**Results:** There were significant caregiver group effects for all variables, except depression and resourcefulness. Grandmothers raising grandchildren reported the most stress, intra-family strain, and perceived problems in family functioning; the worst physical and mental health; a tendency toward more depressive symptoms; and the least reward and subjective support. Across groups, there were significant time effects for self-rated and physical health and for stress. Transitions to greater caregiving

**Tam H. Nguyen, RN, MSN/MPH, PhD (c)**  
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## **State of the Science: Health Literacy Measures**

### **Abstract**

**PURPOSE:** The purpose of this paper is to review and critically evaluate the current state of the science in health literacy measures- specifically as it relates to the conceptual underpinnings and context of health literacy. Furthermore, the review assesses how well measures are able to capture health literacy in populations with limited English proficiency, a sub-group that has been known to be at high risk for limited health literacy.

**METHODS:** To gain insight into the current state of the science, PubMed, PsycINFO and SCOPUS data-bases were searched for health literacy measurement studies from 1975 to 2007.

Keywords used alone and in combination included: health literacy, instrument, measure, scale, assessment, and tool. Additionally, reference lists of all eligible studies were reviewed and experts in the fields were contacted. Health literacy measures were reviewed and evaluated based on conceptual underpinning, context, psychometric properties, and sensitivity to capture health literacy among populations with limited English proficiency.

**RESULTS:** There are 13 known measures of health literacy, four of which are shortened versions of original measures. The psychometric properties of the measures varied (Cronbach's  $\alpha = 0.57-0.98$ ). Four overarching conceptual domains were found in the measurement of health literacy: print literacy, oral literacy, numeracy and cultural/ contextual knowledge. However, none of the measures were comprehensive, measuring at best only three out the four domains. The majority (8) of the health literacy measures are global in nature, while both the direction and trends are moving toward measures that capture health literacy in a specific context. Few measures are sensitive to people with limited English skills, and none have been translated into languages other than English and Spanish. Additionally, validations of all the measures have come from samples comprised of mainly Caucasians, African Americans, and Hispanic Americans.

**IMPLICATIONS:** These findings may result in faulty health literacy measures, specifically among ethnic minority populations. Future work in health literacy instrumentations should focus on comprehensiveness in order to capture the essential underlying conceptual domains. Additional future validation studies should consider sampling from more ethnically diverse populations. Furthermore, the phonetic structure of the participants' primary language should be considered when validating these tools. Lastly, future studies should also examined if currently available tools are sensitive enough to capture variability among those with very limited English proficiency.

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### ***Living Kidney Donors' Perception of Donation Experience***

#### **Abstract**

**Background:** In 2007, the United Network for Organ Sharing (UNOS) developed a survey focusing on post-donation physical health in living kidney donors. Donor perspectives however, remain understudied. Therefore, the purpose of this study was to validate eight questionnaire items to assess donor candidates' pre-donation education, postoperative pain management, and overall satisfaction with donation and propose their addition to the UNOS survey for further testing.

**Methods:** Analysis of a subsample of seven kidney donors three months after surgery from a longitudinal study of living donor decision making and outcomes. Comparison of responses from in-depth interviews about the donation experience with donors' responses to eight Likert-Scale items measuring perceptions of pre-donation education, pain management, and overall donation experience.

**Results:** Overall, responses to the Likert-Scale items were consistent with qualitative findings. Six out of seven donors reported they were satisfied with pre-donation education and experienced less pain than expected. However, during qualitative interviews, two participants reported they experienced more post-operative pain than expected. Scores on items assessing participants' overall satisfaction with the donation experiences were consistent with qualitative findings and suggested satisfaction.

**Conclusions:** Donors' perceptions of pre-donation education, postoperative pain management and overall satisfaction with the donation process appear to be accurately measured with the questionnaire items used in this study. The authors recommend these items for inclusion in the UNOS post-donation survey for further testing to assess these important dimensions. Findings also suggest a need to explore pain management in the first two days following surgery.

#### **Parent Study Title and Funding:**

Factors Related to Living Organ Donor Decision Making and Outcomes, NINR, NIH, R01 NR008727, MT Nolan, PI

**V. Lynn Peterson, MPH, BSN student V. Lynn Peterson<sup>1</sup>, Arseima Y. Del Valle-Pinero<sup>1</sup>, Angela C. Martino<sup>1</sup>, Kong Chen<sup>2</sup>, Wendy A. Henderson<sup>1</sup>**

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## **Genetic Expression of Obesity Biomarkers in Patients with Low and High Percentage of Body Fat**

### **Abstract**

Obesity continues to increase in epidemic levels worldwide. Current studies that use Body Mass Index (BMI) as a standard for defining the overweight phenotype are limited in that patients with high muscle mass may be inappropriately classified as overweight/obese. The hypothesis is that persons with a high BMI with low body fat will have different genetic expression compared to those with high BMI and high body fat. This pilot study aims to explore differences between percentage of body fat compared to BMI and the relationships to specific genetic expressions of obesity. The sample includes 16 patients who underwent whole-body air displacement plethysmography (BOD POD) for determining percentage of body fat. Height and weight was measured to calculate BMI, which is defined as weight in kilograms divided by height in meters squared. Morning fasting serum was collected peripherally using PAXgene™ tubes. After RNA extraction, a custom quantitative real-time PCR array was then used to determine gene expression in 96 genes related to obesity. Groups were matched by age, gender, and race. Gene expression correlations between percentage of body fat and BMI were compared. The differences will be presented based on log variations in expression of obesity related genes. Anthropometric measurements that more accurately determine a person's body fat percentage is useful in appropriately phenotyping patients and thereby effectively differentiating genetic expression with respect to obesity (i.e., increased body fat). The findings from this pilot study may lead to insight into the management and treatment of obesity related health issues.

**Rita H. Pickler, PhD, FAAN; Mary Jo Grap, PhD, FAAN; Nancy McCain, PhD, FAAN, Debra Lyon, PhD; Cindy Munro, PhD, FAAN; Ronald K. Elswick, PhD**  
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### **P30 Center for Excellence: Biobehavioral Approaches to Symptom Management**

#### **Abstract**

The P30 Center of Excellence for Biobehavioral Approaches to Symptom Management (CBCR) at Virginia Commonwealth University School of Nursing builds on and takes advantage of the synergy developed, resources garnered, and systems developed during our successful P20 Exploratory Center for Biobehavioral Clinical Research (P20 NR008988, N. McCain, PI, 2004-2009). The CBCR focuses on further expanding biobehavioral research capacity for the study of fatigue, a biobehavioral, patient-reported outcome that adversely influences a broad array of health outcomes. This focus is enacted through the work of its cores for Biobehavioral Science (BSC), Biobehavioral Measurement (BMC), and Data Services and Analysis (DSAC) and, via the Administrative Core (AC), through the implementation of five, Center-funded research projects studying: fatigue in women with fibromyalgia; women with breast cancer; pregnant women; women with cardiometabolic risk; and adolescents and young adults with sickle cell disease. We have developed advanced systems for analyzing multidimensional biomarkers and as well as outcomes across a variety of populations and settings and have extended our knowledge of biobehavioral science with current state-of-the-science as well as emerging methods, measures, and technologies. The Center guides the development, integration, synthesis, and dissemination of current and evolving biobehavioral scientific domains, including advances in measurement and data analysis of fatigue and associated phenomena and provides consultation to scientists in the larger biobehavioral research community.

**Nancy King Reame, MSN, PhD**  
*Columbia University*

### **Training Nurse Scientists in Interdisciplinary & Translational Research (TRANSIT)**

#### **Abstract**

**Purpose:** The National Research Council (2005) has recognized the need to change the career trajectory for nurse-scientists, with a greater emphasis on interdisciplinary research. In 2006, the AACN recommended that education for interdisciplinary research must be part of doctoral and postdoctoral nursing education. Prompted by the growing complexity of health problems in underserved minority populations, and supported by a 3-year grant from the Health Research Services Administration (HRSA) for advanced nursing education, Columbia University School of Nursing's PhD program and Hunter College's Master Programs have partnered together to train the next generation of nurse scientists. TRANSIT's goal is to increase the number of nursing faculty prepared to conduct interdisciplinary, practice-relevant research that benefits underserved urban communities. This federally-funded program aims to reduce health disparities in the Northern Manhattan area of the City of New York, a designated Health Professional Shortage Area.

#### **Methods:**

With the help of community partners and an interdisciplinary Advisory Board, the program takes advantage of NIH-funded faculty research programs which target health problems critical in the NYC minority communities such as infectious disease, obesity, diabetes, hypertension and contraception. Currently-enrolled minority doctoral students play a central role in recruitment and retention activities, serving as focus group leaders, seminar speakers, and academic ambassadors for potential applicants. An evaluation plan designed to assess programmatic goals and student competency skills is in place.

**Results:** Five TRANSIT minority fellows are enrolled. Descriptive data will be presented on program characteristics.

**Conclusions:** Graduates will be prepared to create the evidence base to improve nursing practice and health care delivery in underserved, urban communities.



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**Yale School of Nursing Center for Self and Family Management of Vulnerable Populations:  
Development of the Science of Self-Management**

**Abstract**

The Yale School of Nursing (YSN) Center for Self and Family Management of Vulnerable Populations evolved from the YSN P20 Center for Self-Management Interventions in Populations at Risk. The over-arching goal is to advance the science of self and family management of vulnerable populations. Thirteen core studies and 25 pilot studies were funded over 8 years and awarded to inter-disciplinary principal investigators and research teams. The studies were based on the published YSN Framework for Self- and Family Management (Grey, Knafl, McCorkle, *Nursing Outlook*, 2006). The pilot studies addressed self-and family management related to a diverse group of chronic medical (cardiovascular, cancer, diabetes, sickle-cell, and hepatitis) and mental health (Tourette's syndrome) conditions, health promotion issues, aging, maternal-child health and methodological questions. Populations were of diverse ethnicity, socioeconomic status, developmental stage, and received care in a variety of health care settings. Studies included mixed methods, descriptive work, clinical trials, and methodological investigations. Outcomes included advancement of the theory and science of self- and family management through multiple publications and extramural research funding, an update of the YSN Self- and Family Management Framework (in progress), a synthesis report of investigator's perspectives on self and family management, and an evaluation of the services provided by the center. The Center has evolved to include increased collaborations with YCCI, Yale's CTSA, increased community-based research, and an enhanced focus on the linkages between biology and behavior associated with self- and family management.

**Carolyn Miller Reilly**

Emory University, Nell Hodgson Woodruff School of Nursing

## **THIRST AND QOL IN PERSONS WITH HEART FAILURE**

**Abstract Aims:** To identify relationships between fluid intake, thirst, and quality of life (QOL) in persons with heart failure (HF) using descriptive and correlation analysis.

**Methods:** As part of a pilot and feasibility study to evaluate fluid restriction in HF, 25 NYHA Class II- IV patients (age 44-83 years, 56% male, 20% minority, mean EF 23.0  $\pm$ 11.7%, on standard HF medications) were evaluated for daily fluid intake using the 3 Day Food and Fluid Record (3DFR). Thirst and HF symptoms were measured with the Thirst Distress Scale (TDS) and Heart Failure Symptom Survey (HFSS), and QOL with EuroQol (EQ-5D) and Minnesota Living with Heart Failure Questionnaire (MLHFQ).

**Results:** TDS scores ranged 6 to 30, mean 15.6  $\pm$  7.7, with 46% indicating moderate to strong agreement of discomfort caused by thirst. Fluid intake ranged 8.62 to 39.69 ml/kg/day (970-2900ml/ day), EQ-5D index ranged .4-1.0, mean .79,  $\pm$ .16, and MLHFQ ranged 3 to 92, mean 46.96  $\pm$ 25.42. Moderate correlations were found between TDS and all HFSS subscales [frequency ( $r=.545$ ,  $p=.005$ ), severity( $r=.538$ ,  $p=.006$ ), interference with physical activity ( $r=.605$   $p=.001$ ), and interference with enjoyment of life( $r=.552$ ,  $p=.004$ )]. Further, TDS was correlated with both the physical subscale ( $r=.458$ ,  $p=.021$ ) and total MLHFQ( $r=.439$ ,  $p=.028$ ). Trends were found between the TDS and both the EQ-5D index( $r=-.336$ ,  $p=.100$ ) and VAS ( $r=-.328$ ,  $p=.110$ ), and in total fluid consumption ( $r=.400$ ,  $p=.053$ ).

**Conclusions:** These data demonstrate that thirst is an issue for persons with HF attempting to follow a fluid restriction. Our findings also suggest that thirst may adversely affect QOL.

**Cielito C. Reyes-Gibby, RN, DrPH**

*Department of Epidemiology, Division of Cancer Prevention and Population Sciences, The University of Texas, M. D. Anderson Cancer Center, Houston, TX, USA*

## **Inflammation Pathway and Symptom Burden in Lung Cancer Patients**

### **Abstract**

Patients with lung cancer suffer from severe and debilitating symptoms. There is compelling evidence that cytokines play an important role in the pathogenesis of cancer-related pain, depressed mood and fatigue-- the most prevalent and debilitating symptoms reported by cancer patients. In this study, we first defined a phenotype for symptom burden by applying cluster analyses on these three symptoms and used a Bayesian statistical methodology to test our a priori hypothesis that SNPs in the inflammation pathway will help predict symptom burden in 599 white Caucasian patients with previously untreated non-small cell lung cancer. Demographic, clinical and symptom data were collected prior to cancer treatment. Pain was rated on an 11-point numeric scale, (0= 'no pain' and 10= 'pain as bad as you can imagine'). Fatigue and depressed mood were assessed using the items "during the past 4 weeks, did you have a lot of energy?" and "during the past 4 weeks, have you felt downhearted and blue?" respectively. Results showed 116 and 183 patients comprised the high and low symptom burden group, respectively. The additive model in 3 genes significantly predicted symptom burden: IL1B T-31C (PPI = 0.72;OR=0.54;95%CI=0.30,0.95; PTGS2 exon 10+837T>C (PPI=0.76;OR=0.50, 95%CI=0.25,0.93) and ENOS untranslated region (A/G) (PPI=0.86;OR=0.48;95%CI=0.27,0.86). Because genetic polymorphisms are stable markers, an understanding of the extent to which genetic variability plays a role in severe symptoms may prove useful in identifying patients at high-risk for severe symptoms and may help in developing individualized therapy for patients who will benefit most from symptom intervention.

**Sheri L. Robb, PhD, MT-BC & Joan E. Haase, RN, PhD, FAAN**  
*School of Nursing, Indiana University, Indianapolis, IN*

## **Theoretical Synergy to Improve Positive Health Outcomes**

### **Abstract**

**Aims:** Investigators seeking to enhance positive health have few models to guide their selection of targeted variables. The purpose of this presentation is to describe the linking of two theoretical models to address the psychosocial adjustment of adolescents/young adults (AYA) undergoing stem cell transplant.

**Methods:** Components of the Haase Resilience in Illness Model (RIM), also called the Adolescent Resilience Model, include protective factors of derived meaning (hope, spiritual perspective), perceived social support from friends and health care providers, family environment (communication, adaptability, cohesiveness), and positive coping (confrontive, optimistic, supportant). Risk factors are illness-related distress and defensive coping. The RIM components are targeted through a therapeutic music video (TMV) intervention based on Robb's Contextual Support Model of Music Therapy. Robb's theory hypothesizes that effective music therapy interventions contain elements of 1) structure; 2) autonomy support; and 3) supportive relationships.

**Results:** Contextual support elements of the TMV intervention potentially influence RIM outcomes of resilience via multiple paths. For example, focus on developing the music video supports AYA transition from defensive to positive coping, offers a means to communicate traumatic events and unspoken thoughts and emotions experienced during diagnosis/treatment, and encourages family and provider support. The intervention may also provide short-term reductions in illness-related distress. These, in turn, can foster the resilience outcomes of self-transcendence, mastery/confidence, and self-esteem.

**Conclusions:** The theoretical synergy described is being used to test the TMV through a multisite, randomized clinical trial and provides a model for the synergistic use of theory to inform intervention and study design.

**Carol E. Rogers, PhD, APRN-BC; Colleen Keller, PhD; Barbara Ainsworth, PhD; Linda Larkey, PhD**

*Arizona State University, College of Nursing & Health Innovation*

## **Sign Chi Do Effects May Be Mediated By Spirituality**

### **Abstract**

#### **Aims:**

Sedentary older adults are at risk of decreased physical function and maladaptation to aging that may lead to loss of independence. Conversely, regular physical activity and spiritual engagement reduces the risk for mortality. Previous studies have not evaluated the joint effects of spirituality and physical function following a meditative movement intervention such as Sign Chi Do (SCD).

#### **Methods:**

A single blinded, randomized controlled trial tested the effects of SCD exercise compared to a sedentary wait-list control group on physical function and spirituality among sedentary community dwelling adults over 55. SCD is a mind-body approach that has multiple health benefits including improving strength and balance. The Roy Adaptation Model guided the design of this 12 week intervention with measurements of physical function [Timed Up & Go (TUG), 6-minute walk (6-min)], and self-concept [Functional Assessment of Chronic Disease Spiritual-wellbeing (FACIT-SP), or Exercise Self-efficacy (ESE)] at baseline, 6 and 12 weeks.

#### **Results:**

Findings on 42 adults ( $X \pm SD$  age  $75.74 \pm 8.29$ ) showed within group difference of TUG for SCD group from baseline to week 12, 14.26 to 12.31 ( $p < .01$ ). There were significant differences between groups at week 12 for TUG (11.05 and 14.24), 6-min (1082.3 and 716.923), and FACIT-SP (42.45 and 34.3) (intervention and control respectively). ESE did not change.

#### **Conclusions:**

Significant differences in FACIT-SP at week 12 indicate SCD improved spiritual well being over time in addition to improving physical function. These findings are important to the design of effective interventions to promote successful adaptation to aging among older adults.

**Cecelia I. Roscigno, PhD RN CNRN<sup>†</sup> and <sup>‡</sup>Teresa A. Savage, PhD RN**

Department of Women, Children, and Family Health Science, University of Illinois, Chicago

## **ETHNOGRAPHY OF SPEAKING AND DIVERSE VIEWPOINTS**

### **Abstract**

**AIM:** The local setting of healthcare often intersects amidst emerging technologies and multi-cultural beliefs, which can result in cultural clashes. Patients and family members can take offense to our imposition of our cultural beliefs on them. When studied, our approach has been demonstrated to have measurable affects on indicators of health. This presentation reports on an empirically grounded qualitative research methodology, well accepted in the field of communications, but novel to nursing and healthcare.

**METHOD:** The theoretical underpinnings and operational methods of ethnography of speaking are reviewed. The author's research with parents of children following severe traumatic brain injury (TBI) is used as one example illustrating the applicability of this research methodology to discovering how health provider's culture is enacted at the local level in speaking interactions. The meaning parents made of these speaking interactions is illustrated by their responses and discussions of expectations.

**RESULTS:** Ethnography of speaking provides an empirical scaffold from which researchers can discern health providers', patients', and family members' interpretive symbols (individual attitudes, beliefs, notions and expectations) regarding various healthcare phenomena. This methodology highlights how meanings are abstracted from culture (systems of attitudes, beliefs, notions and expectations) and intersect at the local level (a particular time and setting) in speaking interactions.

**CONCLUSION:** What is learned from any nursing research guided by this methodology would serve in the development of more culturally sensitive interactions with patients and their family members, as well as nursing intervention programs that are more relevant to their expectations and needs.

**Leorey N. Saligan, PhD, RN, CRNP**  
*National Institute of Nursing Research*

## **Investigating Molecular-Genetic Correlates of Cancer-Related Fatigue**

### **Abstract**

**AIM:** To describe the relationships between perceived fatigue and gene expression profiles of individuals with localized prostate cancer receiving external beam radiation therapy (EBRT).

**BACKGROUND:** Fatigue is a common, debilitating complaint that is known to impact an individual's functional status and quality of life. The symptom of fatigue alone, independent of medical diagnosis, can lead to disability as impaired function compromises performance of occupational roles. About 25 to 99% of patients with diverse types of cancer experience fatigue during treatments, and up to 38% of cancer survivors experience severe fatigue. It is an unmet clinical need; it is therefore a logical target for intervention.

**METHOD:** Active protocol (NCT00852111) exploring fatigue symptoms in patients with localized prostate cancer and its relationships with changes in gene profiles before and after EBRT. Revised Piper Fatigue Scale was used to measure fatigue. Gene expression analyses using microarray using Affymetrix GeneChip® human genome U133 Plus 2.0 array was conducted on the peripheral blood sample collected using Paxgene tube® in seven timepoints (baseline, first day after receiving first EBRT dose, day 7, day 14, day 21 or mid-EBRT, day 42 or end of EBRT, one month post treatment).

**FINDINGS:** Fatigue scores of patients with localized prostate cancer peaked at day 21 (midpoint) of EBRT (mean=2.78, SD=2.02) and went down just above baseline (mean=1.63, SD=1.85) 1 month post treatment (mean=1.70, SD=2.88). Gene expression analyses using microarray of peripheral blood samples of individuals with prostate cancer reveal relationship between overexpression of genes that are related to inflammation, circadian rhythm, apoptosis and mitochondrial function and their fatigue symptoms as measured in several timepoints during localized radiation therapy.

**CONCLUSIONS:** Initial findings of an active fatigue study provide evidence of possible biomarkers that explain the mechanisms involve in fatigue. Future studies will explore possible interventional targets for novel therapies.

**Rachel F. Schiffman, PhD, RN, FAAN; Christine Kovach, PhD, RN, FAAN; Polly A. Ryan, PhD, RN; Kathleen J. Sawin, PhD, RN, FAAN; Suzanne Feetham, PhD, RN, FAAN, Sally P. Lundeen, PhD, RN, FAAN**

*College of Nursing, University of Wisconsin-Milwaukee*

## **Advancing the Science of Self-Management through Technology, Intervention and Decision Support**

### **Abstract**

Scientists in the Center for the Enhancement of Self-Management in Individuals and Families (SMSC) at the University of Wisconsin-Milwaukee conduct research on interventions, technology, and decision support systems to enhance self-management of health behaviors and improved health outcomes. Self-management is a complex and multidimensional construct including processes that enhance knowledge and beliefs, self-regulation, and social facilitation; intervention programs that directly or indirectly impact self management behaviors; and outcomes achieved through engagement in healthy behaviors. Self-management may be performed by individual and family engagement in learned behaviors and may be facilitated through supportive partnerships or systems. The four projects supported by the SMSC each focus on one or more aspects of the Center's Self-Management Model. One project tested the feasibility of an intervention for self-management for symptoms of heart failure. Another explored the self-management of obstructive sleep apnea. There are two ongoing studies. One is focused on the development of an intervention for self-management of post-partum fatigue incorporating sleep; the other is focused on an intervention for family caregiver recognition and management of the unmet needs of persons with dementia. The SMSC has established a Biobehavioral Laboratory that will enhance the capacity to include biophysical measures into interdisciplinary programs of research. Research in the SMSC is grounded in the premise that understanding and influencing health outcomes is enhanced through examining the effects of interactions between biology, behavior and context. Center scientists work to understand the complex mechanisms involved in these relationships while developing healthcare innovations that support self-management.



**Elizabeth A. Schlenk, PhD, RN**

*University of Pittsburgh School of Nursing*

## **Relationship Between Cognition and Adherence**

### **Abstract**

**Aims:** The purpose was to explore if cognitive function was related to adherence, ease of use, and preference for use of physical activity assessment methods in adults  $\geq 70$  years.

**Methods:** A correlational descriptive design was used in this ancillary study. Subjects were assigned a randomly ordered sequence of six methods using each method for one week. Subjects were instructed to record 3x daily the number of times they walked  $\geq 10$  minutes using paper, PDA, Web, and telephone diaries and to wear an accelerometer and pedometer daily when awake. Percentage adherence to instructions was computed for correct number of: times used, days used, and on-time use. Subjects completed Likert scales on ease and preference of each method. Nine subjects completed the Repeatable Battery for the Assessment of Neuropsychological Status.

**Results:** Cognitive function was not significantly related to times adherent. For days adherent, language was associated with telephone diary ( $r_s = -.67$ ), attention was correlated with PDA diary ( $r_s = .80$ ), and delayed memory was related to paper diary ( $r_s = .68$ ). For on-time adherence, language was correlated with paper diary ( $r_s = -.69$ ). Attention was correlated with ease of telephone diary ( $r_s = .68$ ). Attention ( $r_s = .70$ ) and language ( $r_s = .82$ ) were related to ease of pedometer. Attention was correlated with preference for web diary ( $r_s = -.79$ ). Language was related to preference for telephone diary ( $r_s = -.67$ ) and accelerometer ( $r_s = -.75$ ).

**Conclusions:** Language, attention, and delayed memory were related to adherence, ease of use, and preference for use of physical activity assessment methods among older adults. Investigators should consider the impact of cognitive function on adherence.

**Chantel M. Snyder RN, BSN**

*University of Pittsburgh School of Nursing*

## **Genomics of the VEGF Pathway in Neonatal Respiratory Distress Syndrome**

### **Abstract**

Neonatal respiratory distress syndrome (RDS) is a multifactorial developmental condition of the lungs that affects up to 60% of premature newborns and significantly contributes to neonatal morbidity and mortality. Evidence implicates genetics in susceptibility to RDS including studies of genetic linkage and clustering of neonatal RDS within families. Successful fetal to neonatal pulmonary transition requires proper vessel formation and sufficient production of pulmonary surfactant. Vascular endothelial growth factor (VEGF) pathway stimulates vascularization in the lung and synthesis of surfactant, suggesting a role in RDS pathogenesis. VEGF protein is significantly decreased in plasma and bronchoalveolar lavage of infants who develop RDS. The proposed study aims to investigate the potential association of genes within the VEGF pathway with neonatal RDS using a nested case-control, candidate gene study. Specific aims are:

- 1) Investigate neonatal genetic variation in genes involved in the VEGF pathway for susceptibility to or protection from RDS
- 2) Use neonatal/maternal dyads and neonatal/maternal/paternal triads to investigate genes involved in the VEGF pathway for susceptibility to or protection from RDS.

DNA samples from the Identification of Maternal and Fetal Genetic Factors in Preterm Birth (Prematurity) and Prenatal Exposures and Preeclampsia Prevention (PEPP) studies will be utilized. High throughput genotyping technology will be used for data collection and regression analyses and transmission disequilibrium testing will serve as analytical approaches.

The impact of this study is a greater understanding of the biological underpinnings of RDS and the potential for using genetic endowment for management of RDS.

**Karen Farchaus Stein**

*University of Michigan, School of Nursing and Department of Psychiatry*

### **EMA: Measurement of Risk Behaviors in Women of Mexican Origin**

#### **Abstract**

**Aims:** Ecological momentary assessment (EMA) is a prospective data collection methodology in which participants record target behaviors as they occur. Although EMA has been used effectively with populations of healthy and ill adults, evidence of the utility of the approach with community-based ethnically diverse samples is lacking. The purpose of the study is to evaluate the validity of EMA to measure disordered eating, alcohol, and tobacco use in young adult women of Mexican origin.

**Methods:** College-enrolled women of Mexican origin (N=100) recorded binge eating, self-induced vomiting, laxative, alcohol and tobacco use immediately after each episode for 14 days. To assess adherence, participants were asked to respond to 3 signals daily. At the end of the EMA period, participants completed retrospective measures of disordered eating behaviors (EDE), alcohol and tobacco (timeline follow-back measures).

**Results:** Binge eating (n=15), tobacco use (n=12) and alcohol use (n=38) were moderately prevalent, while persons engaged in self-induced vomit (n=6); Laxative use (n=6) were less common. Correlations between EMA and timeline follow-back measurement of alcohol (# drinks)( $r=0.86$ ,  $p<.001$ ) and tobacco use ( $r=0.76$ ,  $p<.001$ ) were strong as were the correlations between the EMA and EDE measures of vomit episodes ( $r = .84$ ,  $p<.001$ ) and laxative episodes ( $r=0.92$ ,  $p<.001$ ). The correlation between the EMA and EDE measurement of binge episodes was small and non-significant ( $r=-0.05$ ).

**Conclusions:** Results suggest that EMA is a valid approach to measure risk behaviors in young adult women of Mexican origin. The low correlation between measures of binge episodes may stem from embarrassment associated with the interview format of the EDE. Additional research related to valid and reliable measurement of this prevalent but potentially embarrassing behavior is needed.

**Alexa Stuifbergen, PhD, RN, FAA**

*The University of Texas at Austin School of Nursing*

**Center for Health Promotion and Disease Prevention Research In Underserved Populations (CHPR)**

**Abstract**

The Center for Health Promotion and Disease Prevention Research in Underserved Populations (CHPR) was established in 1999 at The University of Texas at Austin School of Nursing to improve the health of underserved people through the development and facilitation of effective interdisciplinary research in health promotion and disease prevention intervention methodology. We defined underserved populations as those that experience barriers related to access to care, continuity of care and suitability or appropriateness of care based on contextual factors that include gender, ethnicity, disability status, geographic location or other circumstances that may lead to marginalization. Between 1999 and 2010 the CHPR funded 36 pilot studies that included more than 1,400 participants from a wide variety of underserved populations. The CHPR provided mentoring and training to build the science of health promotion in underserved populations through workshops, conferences, fellowships and summer research institutes to more than 134 investigators (40% are minority scientists) from 34 institutions (including nine minority serving institutions) representing 14 different disciplines. Dissemination of findings from these innovative training and research programs has included peer-reviewed publications, traditional research conferences for researchers and clinicians, four health promotion laboratories for researchers and publication of a series of peer-reviewed supplements to an interdisciplinary journal focusing on promoting health of selected underserved populations (persons with chronic and disabling conditions, women, adolescents and older adults). The CHPR has fostered a collaborative interdisciplinary environment and significant contributions to the science of promoting the health of underserved populations.

Debra N. Thompson, RN, PhDc, CNAAB-BC<sup>1</sup>, Rangaraj Ramanujam, PhD<sup>3</sup>, Susan M. Sereika, PhD<sup>1</sup>, Helen K. Burns, PhD, RN, FAAN<sup>1</sup>, Gail A. Wolf, DNS, RN, FAAN<sup>1</sup>, Tami Minnier, RN, MSN, FACHE<sup>2</sup>, Leslie A. Hoffman, PhD, RN, FAAN<sup>1</sup> :

<sup>1</sup> <sup>1</sup>School of Nursing, University of Pittsburgh, Pittsburgh, PA, <sup>2</sup>UPMC Health System, Pittsburgh, PA and <sup>3</sup>Owen Graduate School of Management, Vanderbilt University, Nashville, TN

## **Nurse Leaders and Safety Climate: A Relational Perspective**

### **Abstract**

**Aims:** Safety climate has been defined as employee shared perceptions of what organizational behaviors are supported and rewarded to prevent harm. The aim of this study was to examine the relationship of frontline nursing leaders and safety climate using the industrial psychology perspective of Leader-Member Exchange (LMX). LMX posits that outcomes are improved when leaders develop high quality, differentiated relationships, based on mutual trust, respect, and obligation with staff members.

**Methods:** These relationships were investigated with a multi-level, cross-sectional design in a sample of 34 unit directors and their nursing staff (N=711) in a 700 bed tertiary care hospital. Data were collected using the Agency for Healthcare Research and Quality Safety Culture Survey (safety climate) and the Leader-Member Exchange Tool (differentiated relationship). Data were analyzed using descriptive and exploratory data analysis and hierarchical linear modeling (HLM).

**Results:** Based on HLM, differentiated relationships do exist between leaders and their respective staff (Mean=3.69, SE=0.059, t=62.53, p<.0001); however, LMX scores demonstrated significant variability both within (Z=17.97, p<.0001) and among (Z=2.80, p=.0026) units. Furthermore, positive relationships were found between the safety climate dimensions and LMX (p<.0001), indicating high quality LMX relationships are associated with positive staff perceptions of organizational safety behaviors.

**Conclusions:** A positive association was found between nurse leader behaviors and safety climate. This observed positive association has important implications for future development of nurse leaders and programs to improve safety. Research is needed to understand how these differentiated relationships can help to improve safety climate and improve nursing practice.

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**Part of Ongoing Study:** Initial findings are reported from a study using the Leader-Member Exchange perspective designed to examine the association of leadership between safety climate and adverse care outcomes. Additional study aims explore relationships between leadership, safety climate, unit and staff characteristics and adverse care outcomes

**Mary E. Thompson**  
*University of Virginia*

## **How Young, Low-Income Mothers' Feed Their Children**

### **Abstract**

**Aim:** The purpose of this dissertation qualitative study was to explore the feeding practices of low-income, teen mothers of preschool-age children. Parental feeding practices are important to study as previous research has found that parent feeding can be a risk factor for some children who develop childhood overweight. The question guiding this study was: "What are the feeding activities of low-income mothers who were teens at the birth of their preschool child?"

**Methods:** This phenomenological qualitative study used an innovative method of self-video documentation, where mothers' videotaped themselves while engaged in activities related to feeding their child. In addition, mothers were interviewed while viewing the videotapes to gain a better understanding of what was happening during the filming. This technique provided an ability to study a wide variety of factors that might have an effect on the mothers' food choices and feeding practices. Data was analyzed using NVivo 8 qualitative software.

**Results:** How and what mothers fed their children related to their own preferences and experiences with food. Financial factors such as food stamps, WIC and availability of foods played a crucial part in feeding practices.

**Conclusions:** Although information gained from qualitative research cannot be generalized to other populations; this study may contribute to nurses' and nurse practitioners' clinical practice as it identifies the need to address behavioral changes with parental food preferences and food choices. In addition, educating mothers about how to purchase healthy foods, under the reality of financial constraints, may improve the quality of food choices in the home.

**Sharon Tollin, MS, ARNP**  
*University of South Florida*

## **Genetic Variants in TNF and Chemotherapy-Related Cognitive Decline in Women with Breast Cancer**

### **Abstract**

Genetic susceptibility, cytokine deregulation, inflammation and endocrine changes have been postulated as mechanisms contributing to cognitive decline after chemotherapeutic treatment for breast cancer. This proposed exploratory study is a longitudinal, repeated-measures research design to evaluate the association between genetic functional polymorphisms in the Tumor Necrosis Factor gene on chromosome 6 and declines in cognition in women receiving chemotherapy treatment for breast cancer. The primary aim of the study is to investigate functional polymorphisms in the Tumor Necrosis Factor (TNFA) and Lymphotoxin-alpha (TNFB/LTA) genes at 6p21.3, serum cytokine levels, cognitive decline, anxiety, depression, psychological well-being and quality of life. TNF $\alpha$  and TNF $\beta$  are pro-inflammatory cytokines, and assessment of biomarkers will include a comprehensive cytokine panel. Individuals receiving chemotherapy after breast cancer surgery will be compared with breast cancer patients who do not receive any chemotherapy and also with unrelated, healthy non-cancer controls. Baseline assessment of all study participants will include TNF genotyping, cytokine levels, cognitive functioning, anxiety, depression, psychological well-being and quality of life. Cytokine levels, cognitive functioning, anxiety, depression, psychological well-being and quality of life will then be reevaluated in all study participants again at 6 and 12 months after baseline. Statistical analyses will include descriptive statistics, analysis of variance (ANOVA), correlation and multiple regression analyses.

**Toni Tripp-Reimer, PhD, RN, FAAN**  
*University of Iowa College of Nursing*

### **Gerontological Nursing Interventions Research Center**

#### **Abstract**

Over its 15 year history, the Gerontological Nursing Interventions Research Center (GNIRC) at The University of Iowa College of Nursing: 1) strengthened infrastructure to support gerontological nursing research; 2) mentored and supported investigators with funding for 72 pilot grants (with additional support from the Iowa Hartford Center of Geriatric Nursing Excellence); 3) facilitated the transfer of knowledge from academia to practice through the development and dissemination of Evidence Based Guidelines; 4) provided training and support in research design and methods; and 5) strengthened collaborations with others in the field through the development of the 17-school consortium in the Regional Training Core. These efforts have resulted in 47 R-Series grants, >500 publications, and 41 Evidence-Based Practice Guidelines.



**Melanie Warziski Turk, PhD, RN**

*Duquesne University School of Nursing*

## **USE OF BEHAVIORAL STRATEGIES FOR WEIGHT LOSS MAINTENANCE**

### **Abstract**

Long-term adherence to the behavioral lifestyle changes that support weight-loss maintenance remains a considerable challenge. The extent to which behavioral strategies learned during weight-loss treatment continue to be used is unknown. Aims: This study examined the use of behavioral strategies for weight maintenance at 18 months after a behavioral weight-loss trial, PREFER. We investigated whether differences in strategy use existed between Blacks and Whites and between successful and unsuccessful weight maintainers. Methods: Race was self-identified as Black or White. Successful weight maintenance was defined as  $\leq 5\%$  weight gain. We measured weight and surveyed participants about the percentage of time in the previous 18 months that they used 16 strategies taught during PREFER. Results: The sample ( $N=107$ ) was primarily White (76%), female (86%), on average 46 yrs. old, and successful at weight maintenance (57%). Only 25% of the 16 behavioral strategies were used for  $> 50\%$  of the time in the 18-month period. Reading food labels while shopping was the most commonly used strategy. Recipe modification was the only strategy that significantly differed between racial groups,  $t_{(105)}=2.01$ ,  $p=.04$ . Black persons used this strategy less frequently ( $M=45.0\%$ ,  $SD=31.0\%$  of the time) than white persons ( $M=56.8\%$ ,  $SD=24.3\%$  of the time). There were no differences in strategy use between successful and unsuccessful weight maintainers,  $p > .17$ . Conclusions: Greater emphasis is needed on the continued use of behavioral strategies for weight maintenance, and including culturally-tailored strategies for recipe modification in weight-loss programs might support the weight maintenance efforts of black persons.

**Patricia C. Underwood PhD (c), FNP, RN**

*Boston College School of Nursing and Brigham and Women's Hospital*

## **Genomic Markers for Insulin Resistance and Hypertension in Humans**

### **Abstract**

**Background and Significance:** The metabolic syndrome is a complex disorder leading to increased morbidity and mortality. Components of the metabolic syndrome are known to be inherited however; the heterogeneous nature of the metabolic syndrome has made the identification of genomic markers difficult. Thus, identifying genomic markers in a well-defined intermediate phenotype of the metabolic syndrome, insulin resistance and hypertension, may improve search efforts. Recent evidence supports an association between three candidate genes, caveolin-1 (Cav-1), peroxisome proliferator receptor-activated gamma (PPAR $\gamma$ ), and angiotensinogen (AGT), with altered glucose metabolism and vascular dysfunction. These genes may serve as markers for the co-aggregation of insulin resistance.

**Research Question:** To examine whether single nucleotide polymorphisms (SNPs) in the Cav-1 gene, PPAR $\gamma$  gene, and AGT gene are associated with an intermediate phenotype of the metabolic syndrome, insulin resistance and hypertension.

**Proposed Methods:** A candidate gene association study will be done using the HyperPath dataset. Caucasian participants with hypertension will be included. Phenotype studies include the Homeostasis Model Assessment model (HOMA-IR) and a hyperinsulinemic euglycemic clamp. Statistical analyses will be conducted using a general linear model accounting for relatedness and adjusting for the following covariates: age, gender, body mass index (BMI).

**Results and Conclusion:** The proposed study may identify genomic markers for the identification of insulin resistance and hypertension enabling individualized prevention and treatment strategies.

**Xiao-Min Wang<sup>a</sup>, May Hamza<sup>a,c</sup>, Tian-Xia Wu<sup>b</sup> and Raymond A. Dionne<sup>a</sup>**

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## **ADVANCING UNDERSTANDING OF SYMPTOMS BIOLOGY TO IMPROVE DISEASE MANAGEMENT**

### **Abstract**

**Aim:** Treatments of symptoms such as chronic pain and fatigue remain unmet medical needs due to lack of knowledge of the underlying mechanisms. This study employed advanced molecular-genetic methods into clinical studies to better understand the biology of symptoms onset, molecular-genetic pathways and to identify novel targets for interventions.

**Methods:** Using microarray and qRT-PCR gene expression analyses, this study evaluated changes in gene expression of a cascade of cytokines following acute inflammation and the correlation between the changes in the gene expression level and pain intensity in a clinical model of acute inflammation.

**Results:** Tissue injury resulted in a significant up-regulation in the gene expression of IL-6 (63.3-fold), IL-8 (8.1-fold) and CCL2 (8.9-fold). The up-regulation of IL-6 expression was significantly correlated to the up-regulation of IL-8 and CCL2. The up-regulation in gene expression of IL-6, IL-8 and CCL2 was positively correlated to pain intensity at 3 hours post-surgery, the onset of acute inflammatory pain. Katorolac did not have a significant effect on the gene expression of IL-6, IL-8 and CCL2 at the same time point.

**Conclusions:** These results demonstrate that up-regulation of IL-6, IL-8 and CCL2 gene expression contributes to the development of acute inflammation and inflammatory pain. The investigative strategy of this study is to advance understanding of the molecular-genetic changes that initiate and sustain symptoms burden and to develop biomarkers for individual variation in symptoms and management. Translational to clinical practice will permit nurse lead symptoms assessment and individualized management of symptoms across diseases and the life span.

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## **MEDICATION-TAKING REGARDING ORAL HORMONAL THERAPY IN BREAST CANCER**

### **Abstract**

**AIMS:** Published reports of medication adherence and anastrozole discontinuation rates do not provide complete or accurate assessment of medication-taking. The purpose of this qualitative, descriptive study is to describe medication-taking experiences for women with breast cancer receiving anastrozole therapy.

**METHODS:** Criterion-related sampling is used to select a representative sample (12-20) of adult, post-menopausal women with early stage breast cancer in western Pennsylvania who completed the first six months of anastrozole therapy in a study evaluating cognitive function related to anastrozole use (R01-CA-107408 Bender, PI). High-, medium-, and low-adherers receiving anastrozole alone or with chemotherapy, as well as those who discontinued anastrozole, are invited to participate in in-depth, audio-recorded interviews. Qualitative content analysis with constant comparison is used to ensure proper fit between categories and the women's view.

**RESULTS:** Nine women aged 58-67 have been interviewed. All underwent surgery and radiation therapy; most (8) received anastrozole without chemotherapy. Preliminary analyses reveal three themes describing the women's individual perceptions of their medication-taking process and motivation: 1) *side effect profile*, including duration, severity, characterization, frequency, causality, and management strategies; 2) *value/importance of medication-taking*, defined as the belief in the relative worth of taking anastrozole, motivation, and/or commitment to treatment; 3) medication-taking as an *individual versus social endeavor*, comprised of personal routinization and a more social "mutual medication-taking" phenomenon. *Treatment imperative*, a subtheme, was identified as a necessity or obligation to take anastrozole.

**CONCLUSIONS:** Study findings will provide the basis for future investigations and individualized interventions for medication-taking of oral hormonal therapies for women with breast cancer.

**FUNDING:** Cognitive Impairment Related to Anastrozole Use in Women, R01 CA 107408 (Bender, PI); Symptom Management, Patient-Caregiver Communication, and Outcomes in ICU, K24 NR010244 (Happ, PI); F31NR011261, A Study of Medication Taking for NSCLC Patients Receiving Oral Targeted Therapy (Wickersham, PI); Elizabeth Lloyd Noroian Scholarship for Graduate Studies in Nursing (2009).

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**Center of Excellence for End-of-Life Transition Research (CEoLTR): Advancing Science across the Life Span**

**Abstract**

The purpose of the CEoLTR is to advance the science of care for people facing the end-of-life transition across the life span. We emphasize patient-centered, family-focused respectful death with planning for end-of-life care that is consistent with the patients' and families' values and priorities (awareness about ways people die, advance care planning) and expected death experiences (palliative care, approaching dying, bereavement). Aims are to: advance nursing science related to the end-of-life transition; strengthen the ethical use of mixed methods by CEoLTR investigators and train novices about ethical issues in end-of-life research and mixed methods measurement of biobehavioral variables, management and analysis of data; expand the capacity to conduct end-of-life research with informatics solutions that contribute to high integrity processes and efficient, valid, and reliable outcomes in institutional and community-based settings; and facilitate dissemination of end-of-life research findings. We will advance the science of disparities in care at end-of-life and support end-of-life research training by providing core services and resources to investigators. The scientific focus is conceptually organized according to an ecologically based, health-related quality of life framework that addresses both person and environmental factors as they interact to affect respectful death outcomes for individuals and families. Studies supported by the CEoLTR are designed to: elucidate underlying physiological, experiential, and behavioral mechanisms that prognosticate or influence approaching death or bereavement; and test culturally relevant interventions for death awareness and respectful death. The interaction of investigators with expertise in diverse groups of subjects will advance the science of end of life.

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## **The Impact of *GJB2* (connexin 26) Variants and Nonsyndromic Hearing Loss**

### **Abstract**

Of the more than 4000 infants born deaf each year, more than half have a hereditary disorder. Approximately 70-80% of hereditary hearing loss is nonsyndromic, but not all hereditary hearing loss is present at birth; some children inherit the tendency to develop hearing loss later in life. Undiagnosed hearing loss and diagnostic delay have a profound impact on linguistic and communicative competence, as well as cognitive and psychosocial development. Hearing loss-associated variants of the gene *GJB2*, encoding the gap junction protein connexin 26 (Cx26), are the most common genetic cause of prelingual nonsyndromic sensorineural hearing loss worldwide. The aims of this study are to determine the association of *GJB2* variants and family history related to hearing loss and to investigate the variability of genotype and severity in infants and toddlers.

A prospective cohort of 410 unrelated children with prelingual nonsyndromic hearing loss will be recruited for genetic evaluation for connexin variant analysis. A control group consisting of genomic DNA from individuals without a hearing disorder will be obtained from the Coriell Institute (Camden, NJ). Polymerase chain reaction (PCR) will identify any underlying genetic mutation and its role in hearing loss. A high prevalence of Cx26/30 hearing loss-associated variants could lead to the inclusion of genetic testing for hearing loss in newborn screening.

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## **Do Grandmothers Need Resourcefulness Training?**

### **Abstract**

Over one million American grandmothers raise their grandchildren and experience overwhelming stress that may adversely affect their health. Interventions to teach them to be resourceful in managing their stress may promote their optimal health so they can continue raising their grandchildren. However, before examining the effectiveness of resourcefulness training (RT), its necessity must be evaluated. **Aims:** This pilot intervention trial with 126 grandmothers examined the need for RT using objective and subjective measures. **Methods:** Data on resourcefulness, stress, and depressive symptoms were collected during interviews with grandmothers before and after RT. Baseline resourcefulness scores indicated level of need for RT; higher scores indicated lower need. Strength and direction of correlations among resourcefulness, stress, and depressive symptoms were examined. Grandmothers who completed the RT were asked about their own perceived need and the need of other grandmothers for RT. **Results:** Baseline resourcefulness scores were normally distributed with only 4% (n=5) in the uppermost 15% of the possible scoring range. Although reasons for ending participation did not include a need for intervention, grandmothers who dropped out scored an average of seven points higher on the Resourcefulness Scale. Lower resourcefulness was associated greater stress ( $r=-.38, p<.001$ ) and depressive symptoms ( $r=-.36, p<.001$ ). Of the 40 grandmothers who received RT, 88% (n=35) reported a felt need for RT; 92% (n=37) believed other grandmothers need RT. **Conclusions:** The results suggest a substantial need for RT in grandmothers raising grandchildren and support moving forward with testing the effectiveness of RT in reducing grandmother's stress and depressive symptoms.

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***Interdisciplinary Rural Healthy Heart Center***

**Abstract**

Heart disease is the leading cause of death in the U.S. and Nebraska. Thus, we created a Healthy Heart Center (HHC) at the University of Nebraska Medical Center.

Aims of the Center are: to facilitate development of infrastructure to support the research in rural Nebraska; and expand interdisciplinary research projects aimed at improving health and quality of life in both healthy and chronically ill rural individuals with or at risk for cardiovascular disease. These aims will be accomplished through the Administrative Core that oversees the Center, and two additional cores: the Building Interdisciplinary Teams Core, which will facilitate mentoring of Center scientists, provide interdisciplinary guidance and consultation, and assist with building interdisciplinary research teams, and the Rural Technology Core, which will maintain, expand, and develop technologies and resources to implement the projects.

Methods: Five pilot studies will be implemented over a 5 year period based on the framework: Intervention Partnerships for Patient and Family Centered Research. Common measures that will be used across all five pilot studies include: demographic characteristics, rurality, self-reported and physiological measures of physical activity, and the EuroQol Questionnaire.

Results: Two pilot studies are being implemented. One study is examining health outcomes in spousal caregivers of coronary artery bypass surgery patients. Another study is examining a weight loss intervention for percutaneous coronary intervention patients. Both studies are using telehealth and monitoring technology.

Conclusions: It is anticipated that the HHC will consolidate research resources in a creative interdisciplinary environment to develop faculty and health promotion/ disease prevention science.